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Learning in Social Movements: A research study of awareness and understanding of a Treatment Literacy programme implemented by the Treatment Action Campaign in the Western Cape in the period 2001 to 2009

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ABSTRACT

This qualitative research study examines six participant's awareness and understanding of a Treatment Literacy (TL) programme implemented by the Treatment Action Campaign (TAC) in the Western Cape in the period 2001 to 2009.

The study investigates what attracted the participants to the TAC; what they learnt and how this was taught; the extent, if any, to which participant's experiences changed their understanding of HIV and AIDS, sexuality, treatment and other health-related practices.

To analyse participants' awareness levels, understanding and experiences, I drew on Freire (1970; 1985) and Mezirow (1991; 1994) adult education literature, more specifically literature addressing the social movements and how activists learn and teach in different context (informal and non-formal) such as Newman (1995) and Foley (1999). These perspectives underpin the central argument of the thesis, namely that adult education is contextual and has impact on awareness, understanding and experiences and in this case HIV and AIDS.

A primary finding of the study is how the participants in the study perceived the world as central to their learning. Learning is thus a substantially personal experience; however, the development of the individual frequently occurs within a group dynamic. Participants felt that being part of TAC and fighting for access to treatment and helping other people who are either HIV positive or affected by HIV and AIDS, helped them in turn to deal with their own challenges of being HIV positive and affected with HIV and AIDS. Being HIV positive and receiving education from TAC has given participants dignity and the necessary consciousness to obtain control of their life. Participants also reported that the TL programme boosted their confidence and raised their level of awareness and understanding of the topic.

Key words: informal learning and non-formal learning, transformation, adult learning, social movements, critical consciousness, health and human rights, HIV and AIDS

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I devote this dissertation to my baby sister, Angeline, who passed on five years ago. A special thank you to all my family and friends that supported me and who advised me during my work on this dissertation. Thank you to the Treatment Action Campaign and the activists that allowed me to interview them. To my supervisor, thank you for being part of my journey and for your patience.

ACRONYMS USED

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
ASASA	Advertising Standards Authority of South Africa
ASSA	Actuarial Society of South Africa
CBO	Community Based Organisation
CEPPWAWU	Chemical Energy Paper Printing Wood Allied Worker Union
COSATU	Congress of South African Trade Unions
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences and Research Council
HTC	HIV Counselling and Testing

MCC	Medicines Control Council
MSF	Médecins Sans Frontières
NEDLAC	National Economic Development Labour Advisory Council
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
PCR	Policy Communication and Research
PMTCT	Prevention of Mother to Child Transmission
PTL	Prevention and Treatment Literacy
SANAC	South African National AIDS Council
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TB	Tuberculosis
TL	Treatment Literacy
TLE	Treatment Literacy Educator
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organisation
WTO	World Trade Organisation

CHAPTER 1

“...I think the most important thing for me was the knowledge building that we were doing in every branch. We hardly had any workshops at community halls, we did it at houses, so each branch we use an hour of training ...” (Violet: 2015; interview)

INTRODUCTION

This research study focuses on and is limited to the experiences of six people who participated in a Treatment Literacy (TL) programme implemented by the Treatment Action Campaign (TAC) in the Western Cape in the period 2001 to 2009. The study, which examines participants’ awareness and understanding of their (learning) experience within TAC’s TL programme, addresses the following: What attracted participants to TAC; how and what they learnt; their perception of the learning process; and whether it had any bearing on their perception of the TL.

BACKGROUND

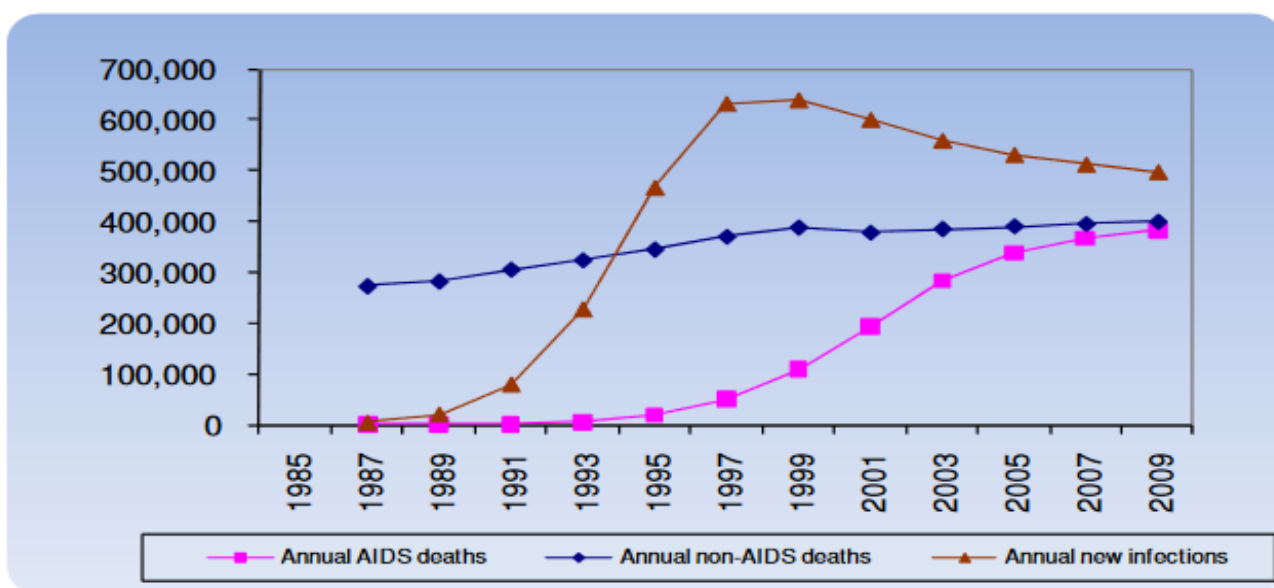
The South African HIV epidemic from late 1990s to 2012

The struggle for HIV and AIDS¹ in South Africa is well documented on account of the state’s controversial stance and response to the epidemic. In addition civil society’s, in particular TAC’s, efforts to secure widespread, government-sponsored access to AIDS treatment was plagued by government inaction and characterised by among other things conflict between and amongst political party politicians, AIDS denialism, a lack of political will and leadership, weak policies and opposition to usage and availability of antiretroviral (ARVs) drugs despite overwhelming scientific evidence of the value of the use of ARVs and the fact that these were available in First World countries. During the late 1990s to mid 2000s South Africa experienced high numbers of HIV infections and many people died of AIDS because of the unavailability of HIV treatment in the public sector and prohibitive costs making them inaccessible to most prior to 2004 (The South African Department of Health Study, 2006). Under President Mbeki’s rule the epidemic was one of the worst in the world (<https://www.theguardian.com/world/2008/nov/26/aids-south-africa>). This situation was further compounded by ongoing harmful interferences such as beliefs or practices mistakenly regarded as being based on scientific method and misinformation between scientists, AIDS organisations and politicians. South Africa currently has the largest HIV epidemic in the world and the impact of this deliberate and interrupted response are still being felt today (WHO/UNAIDS/UNICEF: 2011).

¹ I use the term HIV and AIDS as it was used in TAC to both describe individuals living with HIV or AIDS or both or affected by or both

In the response to the pandemic over the past 25 years, organisations set up by people infected and affected have often been the first and most effective actors. Examples include the San Francisco AIDS Project, Gay Men’s Health Crisis and ACT UP in the US; the Terrence Higgins Trust in the UK, TASO in Uganda and Treatment Action Campaign in South Africa (Squire: 2007). The World Health Organisation (WHO)² only took HIV to the developing world in 1986 (Iiffe: 2006; 68); the first WHO, World AIDS Day was declared in 1988. Organisations such as the Red Cross and Médecins Sans Frontières³ (MSF) have been leaders in HIV education and treatment. MSF started ARV programmes in 2000 and by 2005 had 31 programmes in 16 countries, mostly free of charge (Médecins Sans Frontières: 2005).

Figure1: AIDS deaths, non-AIDS deaths and annual new infections, South Africa, 1985-2009



SOURCE: ASSA model, 2003

ASSA (2003) model estimates illustrate a steep rise in new HIV infections from 1991, peaking at slightly over 600,000 of the population in 1999, declining slowly from then onwards to rest at just under 500,000 persons in 2009. The steep rise in AIDS deaths starts from 1999 at around 100,000 persons, to level out in 2009 at nearly 400,000 people. By 2003 the annual numbers of projected AIDS deaths was equal to projected non-AIDS deaths from all other causes, and could surpass these⁴ (ASSA: 2003; summary statistics).

² An agency of the United Nations established in 1948 to promote health and control communicable diseases. It assists in the efforts of member governments, and pursues biomedical research through some 500 collaborating research centres throughout the world. Its headquarters are in Geneva.

³ MSF also known as Doctors without Borders is an international, independent, medical humanitarian organization that helps people worldwide where the need is greatest, delivering emergency medical aid to people affected by conflict, epidemics, disasters, or exclusion from health care. MSF established the first antiretroviral programme in Khayelitsha, Western Cape, South Africa.

⁴ I am quoting these statistics as it falls within the period of my research

(Shisana, Rehle & others: 2009) agreed that in South Africa, during the early years of the HIV pandemic and as late as 2009/10, there was little consensus within the research community regarding the best tools and methodology for the direct measurement of HIV incidence with the result that statistics are highly contested.

Policies development and programmatic responses in South Africa

The implementation of a number of new policies and pieces of legislation aimed at changing the public health care sector in South Africa has been done. The notable policy successes include among others the scaling up of the Anti-Retroviral Treatment (ART) roll out, revitalization and refurbishment of hospitals, and the development of key health care facilities and services. However, inequities remained substantial in both public and private health care provision, which suggests that many of these policies and laws have not achieved their intended purpose of transforming the healthcare system and addressing the inequalities inherited from apartheid.

When TAC was launched, its main purpose was to ensure access to safe and effective HIV treatment in particular. TAC used strategies like community and social mobilisation, education, research, use of the media and the South African Constitution and law. Although antiretroviral access is now official policy, the government did not respond to TAC's demands at the time. In 2001, TAC took the Minister of Health, Manto Tshabalala Msimang, to court and won the case on the 5th July 2002 (PMTCT - Minister of Health v Treatment Action Campaign (TAC) (2002) 5 SA 721, Life, Right).

TAC mobilised 15 000 people on the 14 February 2003 in their campaign "Stand up for our Lives" and marched to the opening of parliament in Cape Town. In their memorandum to government, TAC made it clear that the state either had to deliver a treatment plan or face civil disobedience. Government only approved anti-retroviral treatment and made it publically available in November 2003 (The South African Department of Health Study: 2006). Consequently, the implementation of a treatment plan only started 2004 and there was no ambitious strategic plan until 2007, when the National Strategic Plan (NSP), was adopted by cabinet. (Fighting for our lives, the history of Treatment Action Campaign: 2010).

Some of the actions taken by government to address HIV and AIDS in the South Africa included among others: the inception of the South African National AIDS Council (SANAC) in 2000; the formation of the National Interdepartmental Committee on HIV/AIDS: the expansion of a Strategic Framework for a South African AIDS Youth Programme and the establishment of the National Action Committee for Children affected by HIV/AIDS (UNGASS: 2010 - United Nations General Assembly Special Session (UNGASS), 2010 (http://data.unaids.org/pub/report/2010/southafrica_2010_country_progress_report_en.pdf)).

STUDY CONTEXT

In this dissertation I look at the TL Programme as delivered by TAC as the context of the study.

The treatment literacy programme involves health education and communication that focus on educating HIV-positive and ordinary citizens about the science of HIV, health and the benefits of treatment. TAC developed a range of simple educational resources including posters, pamphlets, booklets, magazines and videos and combined these with an extensive training programme. Treatment literacy is not taught in a neutral or biomedical fashion but is information about the science of medicine and health and is linked to political science, human rights, equality, and the positive duties on the state (<http://www.section27.org.za/wp-content/uploads/2010/04/journal-HR-practice-heywood.pdf>). TAC used the TL programme as an instrument to rally communities to demand HIV treatment. The programme created a cadre of highly informed activists that openly challenged the misinformation put out by government officials, scientists, religious leaders, politicians and traditional leaders during the years of denialism (Fighting for our lives, the history of Treatment Action Campaign: 2010; 32-33).

The model that was adopted came from the United States of America, where AIDS activists, led by people with HIV, had pioneered the idea of ‘treatment literacy’ among people with HIV. Treatment literacy recognises that in order to fight for rights effectively, people are also required to understand the science of HIV, what it was doing to their body, the medicines that might work against it, and the research that was needed. Emulating this model, TAC became the first AIDS activist organization to pioneer the concept and practice of HIV ‘treatment literacy’ in a developing country. Links were made with groups such as the Gay Men’s Health Crisis (GMHC) and ACT-UP, who in 1999 came to South Africa to provide training to the first cadre of TAC treatment literacy activists (<http://www.section27.org.za/wp-content/uploads/2010/04/journal-HR-practice-heywood.pdf>).

TACs Treatment Literacy Programme

The following section provides an overview of the TAC TL programme.

The Treatment Literacy (TL) Programme is one of TACs primary community outreach programmes. This programme was conceptualised and implemented to coincide with the introduction of ARVs into South Africa’s public healthcare system. Its aim was to assist with the dissemination of information on ARVs, their side effects, benefits, and the need for strict adherence, as well as other important information about health and patient rights. The TL programme also addressed the lack, among the South African general public, of scientific and evidence-based knowledge on TB and HIV and AIDS prevention. In addition, the programme provided public education and training and monitored levels of HIV and TB services at the facilities in which TAC operated – predominantly in underprivileged areas and townships.

Both the work of the Treatment Literacy educators (TLE) and the programme are multi-dimensional. This is because on the level of service delivery, doctors and nurses do not have the capacity to provide sufficient counselling and education for community members both infected and affected by HIV and AIDS. Therefore TAC worked hard to set up a Treatment Literacy programme which operated in clinics, communities, and support groups amongst others. Through on-going group and individual education – in clinics, support groups and other community structures – people are able to obtain information from educators on a range of topics including: appropriate medication, prevention, adherence, Tuberculosis (TB), maternal health and many other health issues.

TL educators, particularly those working in clinics, are also able to ascertain and report back on the deficiencies in the public services system in order to inform TAC campaigns. Lastly, TL educators form a vital part of branch and district campaigns and structures and do on-going education in the various structures of the organisation (TAC: 2008).

Aims of TACs TL Programme

Treatment Literacy was based on the idea of the positive benefits of public health education and information. The TL Programme's main function was to empower citizens and groups of people to acquire power over their health by increasing their understanding of HIV and AIDS prevention, care and treatment, as well as the rights and responsibilities of patients and healthcare professionals respectively. The programme primarily targeted individuals who visit public health facilities and other public places where communities gather. Secondly, the TL programme provided HIV and AIDS education and training to TAC members, support groups, Community Based Organisations (CBOs) and other Non-Governmental Organisation(NGOs), capacitating them to in turn educate the community-at-large.

Other objectives of the TL programme included:

- Providing up-to-date, simplified, health information based on best practice, evidence-based science, which was used to challenge the myths, fears and misconceptions that foster HIV denial and stigma and add to the spread of HIV. This information was also intended to equip individuals and communities with the information needed to make informed decisions about their health.
- Training a cadre of people, including TAC branch members, Peer Educators, Treatment Literacy Practitioners and Trainers, to disseminate simplified health information.
- Providing information on the challenges and successes within public health-care facilities and communities, specifically around execution of the National Plan on HIV and AIDS and informing the advocacy work of the TAC at a community, district, provincial and national level (TAC: 2008).

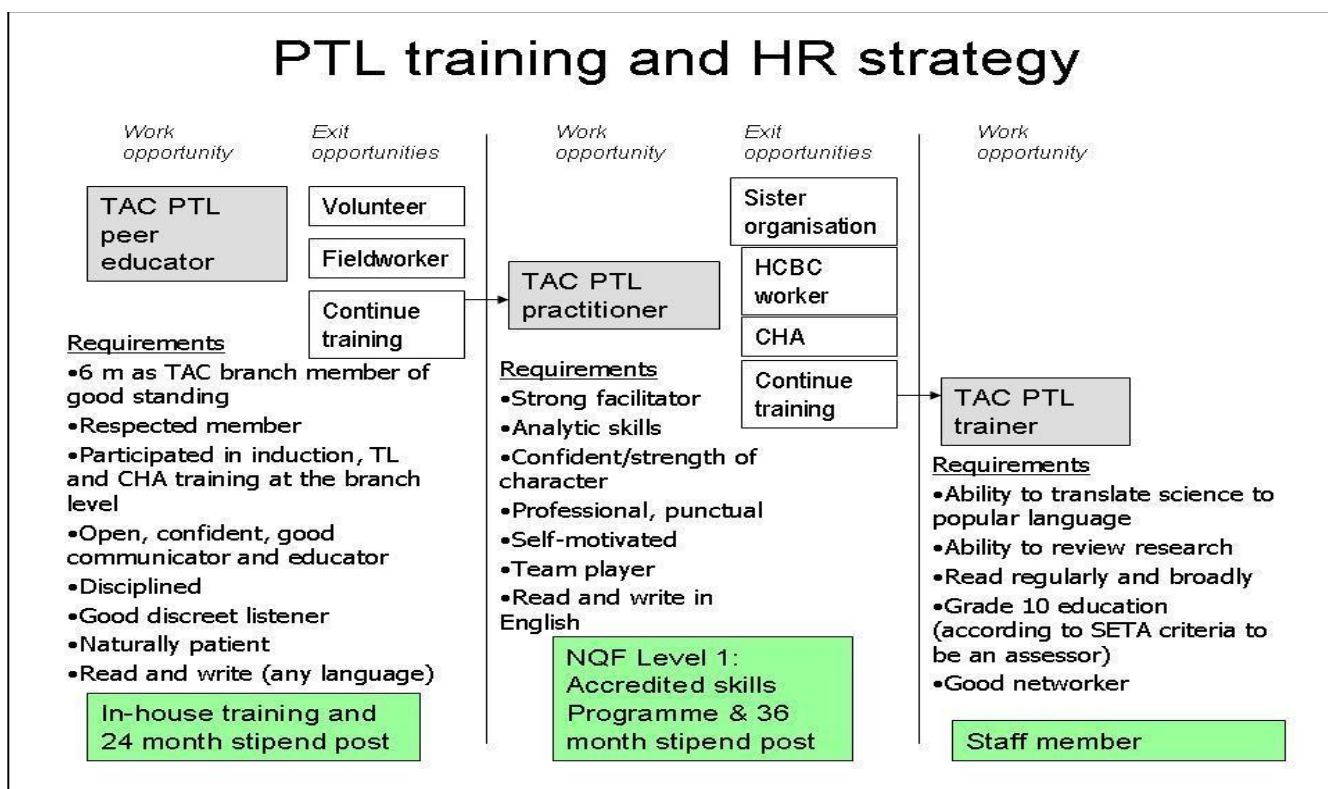
The programme informs people through the following mediums: face-to-face education and information sessions, distribution of HIV and AIDS material, workshops and training on a range of topics including

many other health related issues. By informing patients and community members of the appropriate HIV and AIDS prevention, treatment and care, TAC is educating, creating a learning community, ensuring people are informed enough to know about, engage with, claim and demand their rights to quality health care (TAC: 2008). Although there is no direct evidence, it is likely that in the absence of such interventions the HIV and AIDS infection and mortality rates would have escalated at a greater rate.

The TAC TL structure

The Treatment Literacy programme is made up of peer educators, practitioners, trainers and coordinators

Figure 2: Illustration of TAC TL structure



Peer educators focused on providing education at sites that were not health facilities – schools, support groups, churches and community organisations. They laid the groundwork in the general community. Ideally there would be one peer educator per Prevention and Treatment Literacy Practitioner (PTLP) located at a health site. Although the graphic shows a stipend for twenty four months it depended on the availability of funding. However there was no funding for peer educators.

Practitioners would focus on clinics and health sites. They would work there four days a week (Monday-Thursday) with Fridays reserved for district meetings to do reporting and in-house training. Trainers would work with partner organisations and TAC branches thereby broadening the pool of literate people and organisations.

Overview of TAC Prevention and Treatment Literacy Curriculum

Figure 3: Example TAC PTL curriculum

Introductory Prevention and Treatment Literacy Training	Advance Prevention and Treatment Literacy Training
<ol style="list-style-type: none"> 1. Human Anatomy – 3 hours 2. The Immune System & HIV – 3 hours 3. Virology – ½ day (3 hours) 4. Opportunistic Infections (OIs) (including treatment and prevention) – 3 hours 5. Sexually Transmitted Infections (STIs) – 3 hours 6. Tuberculosis (TB) – 3 hours 7. Antiretroviral Therapy for Adults – 3 hours 8. Antiretroviral Therapy for Infants & Children – 3 hours 9. Prevention of Mother-to-child-transmission (PMTCT) – 3 hours 10. Epidemiology of HIV – 3 hours 11. Global & National Governance – 3 hours 12. Facilitation Skills & Popular Education – 3 hours 	<ol style="list-style-type: none"> 1. Immunology – x⁵ hours 2. Virology – x hours 3. Research – x hours 4. TB & HIV – x hours 5. ARVs & side effects – x hours 6. Pharmacology – x hours 7. Clinical Trials – x hours 8. Women & HIV (Women’s Reproductive Health Rights) – x hours 9. Human Rights – x hours 10. National Strategic Plan – x hours 11. Global Governance – x hours 12. Using our Materials – x hours

RESEARCH MOTIVATION

It is important to acknowledge that I was, at the time of writing up this research, an employee of the Treatment Action Campaign and have been closely and actively involved with the organisation since the early 2000s - a time when treatment for HIV and AIDS was not readily available in the public sector. Before joining TAC, I was an HIV counsellor within an NGO that provided HIV counselling services in the public health facilities in Cape Town, Western Cape. In 1999, I was part of the cohort of individuals who supported the health facility to set up a support group for individuals living with HIV and AIDS. Outside of TAC and throughout my involvement with TAC, I have seen how persons living with HIV and AIDS struggled and suffered, in large part because they could not access antiretroviral treatment, and at the time ARVs were not available at our local health facilities. I saw firsthand how the HIV support group I coordinated shrunk from twenty people to virtually none due to deaths that could have been prevented if treatment was accessible. I have seen how Opportunistic Infections exacerbate the condition of people

⁵‘x’ meaning the time depends on the trainer and the class

living with HIV and AIDS and how disempowering it felt to only be able to provide people in extreme pain with Bactrim and Multivitamins. I attended the funerals of so many members of the HIV support group that I started to feel a sense of hopelessness – and throughout this time ARVs were still not available. My activism was and continues to be both very personal and simultaneously healing.

According to the South African prevalence, incidence and behaviour survey that was done in 2012, South Africa now has one of the most widespread public ARV roll-out programmes in the world, high HIV prevalence rates, particularly amongst the youth, remain a significant concern (Shisana O, Rehle T, Simbayi L.C, Zuma K & Jooste S: 2012). Through this study I hope to identify what lessons, if any, can be discerned from the accounts of the men and women who went through the TAC TL programme and participated in the TAC TL campaign. Because I have actively been involved in TAC's campaign for the availability of HIV and AIDS treatment in the public sector, I have firsthand experience of the difference HIV education and information made in the lives of ordinary people. I am therefore hopeful that some of these lessons remain relevant for the current HIV prevention struggle.

I would like to believe that as a country we have learnt from our mistakes and that these lessons will enable us to plan more effectively for the future.

PROBLEM STATEMENT

South Africa's institutionalised racial discrimination against all black people, from 1948 to 1994, affected the health and healthcare services of black communities in multiple and considerable ways, including but not restricted to the following: poor social circumstances that caused and contributed to ill health; the separation of health services; inadequate healthcare facilities and services for black communities and generally unequal/disproportionate spending on their health services. All of this was exacerbated by the inability of professional health bodies and civil society to efficiently face up to apartheid-entrenched healthcare policies and practices. More than 20 years after the advent of constitutional democracy in 1994, South Africa is still recuperating from the numerous human and health rights violations that took place systematically under the apartheid regime (Hassim, Heywood & Burger: 2007).

As stated by the South African National HIV and AIDS Prevalence, Incidence and Behaviour Survey, 2012, the quantity of South Africans living with HIV increased from 10.6% in 2008 to 12.2% in 2012. They attribute the increased infection rate to the shared effects of new infections and an effectively extended antiretroviral treatment (ART) programme. But the rate at which new HIV infections are acquired, or the HIV incidence rate, is a concern, with the HIV incidence rate among females aged 15 to 24 being more than four times higher than the incidence rate found in males in this group. For instance, among the teenage population, the difference between the HIV prevalence between girls and boys is even advanced: girls have eight times the infection rate of their male counterparts.

In South Africa there are still high numbers of people who stop taking ARV treatment and attending care. People stop taking their medication for various reasons. These reasons range from being pregnant at start of ARV treatment or having a low CD4 count⁶ at entry into care, a lack of disclosure of HIV status, and inflexible clinic hours. If South Africa is expecting to reduce the number of new HIV infections dramatically, this must involve scaling up of combination HIV prevention interventions. It must address the gaps in HIV testing; it must start people on antiretroviral treatment and make sure that they remain on it; it must ensure that people maintain virological suppression and, lastly, it must strengthen its strategies around prevention.

In summing up, the result of the South African National HIV/AIDS Prevalence and Behaviour Survey, 2012 report underscores that while the country was on the correct pathway with the supply of Antiretroviral Treatment (ART), national HIV counselling and testing (HCT) efforts, greater access to Prevention of Mother to Child Transmission (PMTCT) treatment, and increased access to other biomedical, behavioural, social, and structural prevention interventions was needed to reduce the high rates of new HIV infections (Shisana O, Rehle T, Simbayi LC, Zuma K & Jooste S: 2012).

PURPOSE OF THE STUDY

The study investigates what attracted the participants to the TAC; what they learnt and how this was taught; the extent, if any, to which participant's experiences changed their understanding of HIV/AIDS and other health-related practices. The research further seeks to explore, examine and document important educational and learning practices from which to draw inspiration for future HIV and AIDS initiatives in the interest of building a critically informed and active citizenry. The study contributes to a growing body of literature on learning in social movements. Lastly, it is hoped that the participants' stories will inspire people infected and affected by the HIV and AIDS disease.

AIMS AND OBJECTIVES OF THE STUDY

The study explores participant's perceptions, awareness and understanding of a Treatment Action Campaign literacy programme they attended in the Western Cape province of South Africa in the period 2001 - 2009. Some of the questions the study seeks to answer include:

- What attracted participants to TAC?
- How and what did they learn?
- How, if at all, did their experience change their understanding of HIV and AIDS and other health related practices?

The study further seeks to investigate participant experiences which may have influenced their, practice, understanding and levels of awareness.

⁶ The CD4 count is a test that measures how many CD4 cells you have in your blood. These are a type of white blood cell, called T-cells that move throughout your body to find and destroy bacteria, viruses, and other invading germs.

Finally, the study will explore the successes and challenges encountered by participants in the course of their learning journey (specifically inquiring into how they become aware and understanding).

RESEARCH QUESTION

This is a qualitative research study that examines six participant's awareness and understanding of a Treatment Literacy (TL) programme implemented by the Treatment Action Campaign (TAC) in the Western Cape in the period 2001 to 2009. The study examined participants' awareness and understanding of their (learning) experience within TACs TL programme and addressed: What attracted participants to TAC; their experience of TAC and their understanding of HIV and AIDS, their community experience and how and what they learned; their perception of the learning process; and whether it had any bearing on their perception of the TL programme.

THEORETICAL FRAMEWORK

A social movement is a large group of people who are organized to promote or resist social change. Knowledge and learning play a significant role in social movements, which frequently use adult education practice to improve people's awareness of the challenges and issues faced by the group and through this to work to change it (Newman: 1995; 255). Since 1998 TAC has used tactics, such as social mobilisation, taking TAC to the people, wearing of the HIV-positive shirt to raise awareness and public education, building branches, active across seven provinces, organised protests and openness about HIV infection, litigation, and attracting media attention for its campaigns. TAC has grown in size, activities and funding. It has substantial full-time staff, administration, governed by a national council and has funded programmes. I posit that TAC is a social movement, in which learning occurs predominantly through social action.

The following theorists inform the theoretical framework of this study:

The theory of Paulo Freire (1970) on conscientisation and practice through radical action shared with decisive reflection, has galvanized emancipatory education around the world. Importantly, the critical theorists talk explicitly to power relations within the learning context. Perhaps the most important knowledge is people learning that they could act and that their actions can make a difference (Fenwick: 2001). The Treatment Action Campaign provides a study of institutionalising civil rights, relating to the government or public affairs of a country, via movement-based and movement-linked agents and practices in institutional design. Paulo Freire (1985; 72) further argues that learning is aimed at understanding oppression with the view to changing society for a better quality of life.

One of the conditions for being human is the ability to give meaning to experiences. Jack Mezirow posits that individuals must think critically about their own experiences. The theory of transformative learning that was developed by Jack Mezirow (1994) describes critical reflection on experience and how women and

men learn as individuals. Critical reflection empowers them to criticise and change assumptions and make a meaningful change.

Community of practice is a term originally developed by Lave and Wenger. It is referred to a group of people who share a concern or a passion for something they do, and learn how to do it better as they interact regularly. The views of Lave and Wenger (1991) on learning, which fall within the Situated Learning theoretical perspective, are relevant to this study because they foreground learning in terms of participation within a group which they term 'a Community of Practice'.

Non-formal learning takes place outside formal learning environments but within some kind of a framework. Newman (1995; 248) advances that non-formal learning occurs when people become aware of the potential for learning in their activities and make a decision to learn from those experiences.

Griff Foley's (1999) work on "Learning in Social Action" makes a particularly important contribution to theorising and making explicit the incidental learning processes arising from and contributing to engagement in a range of social struggles. Foley points out that although learning through involvement in social struggles can transform power relations, it can also be contradictory and constraining. Foley further emphasises the importance of developing an understanding of learning in popular struggle. His valuing of incidental forms of learning, attention to documenting, making explicit and knowledge production is consistent with others like Smith (1999); Kelley (2002); Bevington & Dixon (2005) and Kinsman (2006), who understand that critical consciousness, rigorous research and theory can and do emerge from engagement in action and organizing contexts, rather than as ideas developed elsewhere being dropped down on "the people" from movement elites.

To analyse the six participants' awareness levels and understanding and experience I will draw on adult education literature, theories and theorists to explore and make the contacts to people's learning and give theories which have direct significance to this study in terms of the site of practice (social movement) and its conceptions of learning and teaching (informal and non-formal). These views will enable me to understand and analyse participant learning, their levels of awareness, understanding and experiences in relation to HIV and AIDS.

RESEARCH METHODOLOGY

This is an exploratory, qualitative research study. Qualitative research methods broadly seek to investigate human behaviour and the social world that people inhabit. This investigation was undertaken through face to face in-depth interviews. The study focused on and was limited to the experiences of six people from different walks of life that went through the Treatment Action Campaign's (TAC) Treatment Literacy Programme (TLP) in the Western Cape.

Six people, who I was familiar with and whom I knew of that went through the TAC Treatment Literacy programme were interviewed. As the researcher I chose participants who were accessible and capable of offering different perspectives relating to awareness, understanding and practice as opposed to a random sample, as outlined by Miles and Huberman (1994).

These participants all came from different communities across the Western Cape and were representative in terms of age, racial and gender demographic; with some participants infected by HIV and AIDS while others were affected by the disease. As advocated by Maykut and Morehouse (1994), the data was interpreted by using thematic content analysis.

I acknowledge and am aware that I approached this study with my own values and perceptions, as a person who was actively involved in the TAC, which may have implications for the study, which I outline in further detail in Chapter 3. My role as a researcher was to construe the findings of participants' consciousness and practice before and after participating in TAC's TL programme and if their experience in the TL programme made a difference in their lives.

OUTLINE OF THE STUDY

Chapter 1: The General Background and introduction includes the introduction, background, study context, research motivation, and problem statement, purpose of study, and aims and objectives of the research.

Chapter 2: The Literature Review provides an overview of the theoretical foundation of the research and situates the research within an HIV and AIDS and Human Rights framework. It further focus on a discussion of learning, site of practice and conceptions of learning and teaching in informal and non-formal contexts and provide a short overview of TAC and a description of how the movement established branches in communities to implement its TL programme and mobilise for treatment.

Chapter 3: Research Methodology and Design includes a description of the research design, the rationale for the methodology used, the target audience, population, sampling, ethical considerations and the data analysis process.

Chapter 4: This chapter will present the research findings of the study from the data gathered using thematic analysis.

Chapter 5: This chapter presents the Discussions, Conclusions and Recommendations of the study and the analysis of the findings as laid out in Chapter 4.

CHAPTER 2: LITERATURE REVIEW

“Personally, the programme changed me, made me more aware, more health conscious...”
(Nomvula: 2015; interview)

INTRODUCTION

This chapter presents perspectives on adult learning and education in social movements through the TAC TL programme and sets out the theoretical foundation of this research study.

As stated in Chapter 1, to analyse the HIV and AIDS awareness levels, understanding and experiences of the six participants in this study, my research will draw on adult education theorists within the critical tradition including: The theory of conscientisation through radical action has galvanized emancipatory education around the world Paulo Freire (1970; 1985). Importantly, the critical theorists talk explicitly to power relations within the learning context. The theory of Jack Mezirow (1994) on transformative learning describes critical reflection on experience; and because my study focuses on the Treatment Action Campaign, a social movement, I also draw on Newman (1995) for his work on knowledge and learning in social movements. I further draw on Foley (1999) for his views on emancipatory learning specifically experience in social action.

The study further draws on a range of research reports and scholars in the field of HIV and AIDS and health, including but not limited to: Dubula (2011), Heywood (2004; 2007), Mbali (2005).

KEY CONCEPTS

The following Key Concepts are important because they are relevant to my study. Some of the key concepts which relate to this research are: critical consciousness, social change, social movements, adult learning, informal and non-formal learning, transformation, HIV and AIDS, difference, empowerment and health as a human right.

Activist – For the purpose of this research, the term “activist” refers to someone who is actively involved in such activities as protest, demonstrations, strikes and sit-ins or the pursuit of a political or social cause intended to achieve political or social change; the definition applies to individuals or members of an organization in this respect.

Adult learning - Adult learning is linked to many other ideas and concepts but this research draws on Mezirow (1991; 1994) who put forward as fact that all learning is based on experience, understanding, knowledge, skills and practice. Learning can therefore be viewed as a process of altering, transforming or modifying an individual’s attitudes, point of view, perceptions and practices with knowledge being

created through critical conversation and discussion, reflection, triggering the transformation of experience which then becomes learning.

AIDS - Abbreviation is Acquired Immune Deficiency Syndrome (AIDS) an infectious disease caused by the Human Immunodeficiency Virus (HIV). There are two variants of the HIV virus, HIV-1 and HIV-2, both of which ultimately cause AIDS. A person who has HIV is classified as having AIDS if one of two things happens: the CD4 count has dropped below 200, or an HIV-related infection or HIV-related cancer develops (Farlex: 2012).

Critical consciousness - Freire's (1970) emancipatory views on education as an instrument for empowerment have had a profound influence on social movements, which fall within the radical critical tradition of adult education. Freire was of the view that the exploited and oppressed must be their own example in the struggle for their salvation (Freire: 1970; 54). Critical awareness and realization can therefore be defined as the ability and capacity to recognise economic, political and social oppression and to take action against the oppressive elements of society.

Difference - In the framework of this research study the meaning of difference implies the qualitative, substantive divergences in participants' awareness and understanding of their experiences within TAC and the TL programme; in other words, an assessment as to whether what they learned and how they learned changed their practices and understanding relating to HIV and AIDS, sexuality, taking treatment and human and health rights.

Empowerment - There is no one definition that encapsulates the meaning of empowerment, as it holds different meanings across different sectors of society. For the purpose of this research study, I describe empowerment as a tool that develops an individual and stimulates their transformation in becoming aware of their potential and the possibilities.

Health as a Human Right - South Africa's Constitution, which contains a Bill of Rights, enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom. Section 27 of the Constitution recognises that: "every person has the right to have access to health care services, including reproductive health care and that no person may be refused emergency health care". In terms of section 7(2) of the Constitution, the state is required to "respect, protect, promote and fulfil" the rights in the Bill of Rights. It should be noted that the comprehensive realisation of the right to health implies recognition of other rights such as for example, right to human dignity, life, freedom from slavery, privacy, housing and education and access to information – all of which are important for good health (Burger, Hassan & Heywood: 2007).

HIV - Abbreviation is Human Immunodeficiency Virus. When an individual is infected with the human immunodeficiency virus (HIV) we say that he or she is HIV-positive or has HIV.

Social change – Social change involves alteration of the social order of a society. It may include changes in social institutions, social behaviors or social relations. Social change may be driven through cultural, religious, economic, scientific or technological forces. This study will draw on the literature of Paulo Freire (1970), which has influenced people working in education, community development, community health and many other fields. Freire developed an approach to education that links the identification of issues to positive action for change and development. People can be inactive beneficiaries of knowledge, regardless of the content, or they can engage in a 'problem-posing' approach in which they become active participants. As part of this approach, it is essential that people link knowledge to action so that they actively work to change their societies at a local level and beyond (Freire: 1970).

Social movements – A social movement is an organised effort by a group of people to achieve a particular goal, typically a social or political one (Webster's online dictionary: 2020). Irrespective of definition, most theorists agree that the fundamental quality that social movements have in common is that they are comprised of "collective activity" of people around a "common interest" (Newman: 1995; 247). Today we have a diverse, complex and a divided civil society that changes over time according to the political, social and economic context and it ranges from small community groupings (burial societies), non-governmental organizations to large formal associations (trade unions), faith based organizations and secular groups (Camay & Gordon: 2007).

Transformation- I draw on Jack Mezirow (1991) for his theory on transformative learning, which he characterises as the process by which we transform our present mind-sets and ways of thinking to make them more inclusive, reflective and open to change, leading to learner empowerment and change both within the learner and the group. This process is based on the ability to question or critically reflect on ourselves and our society.

ORGANISATIONAL CONTEXT WITHIN WHICH LEARNING HAPPENS: TAC & its TL PROGRAMME

This section provides a brief summary of TAC and a description of how the movement established branches in communities to implement its TL programme and mobilise for treatment.

OVERVIEW OF THE TREATMENT ACTION CAMPAIGN

TAC's aim when it was formed in 1998, was to widen access to (i) ARV drugs in order to prevent mother to child transmission (PMTCT case, see Minister of Health v Treatment Action Campaign (TAC) (2002) 5 SA 721, Life, Right), and (ii) post-exposure prophylaxis following sexual assault and for use in combination drug therapy.

At the time TAC was formed, South Africa was confronting a looming health crisis, for which reason TAC used rights-based discourse to frame its campaigns. TAC was a broad-based network consisting of

trade unions, religious organisations, human rights groups, and health professionals among others. TAC, with the AIDS Consortium, used a multi-pronged strategy, which included among others calling for disclosure and openness about HIV infection, strategic legal action, drawing media interest for campaigns through such tactics as rolling mass marches, and calling internationally for symbolical solidarity with its cause. Mbali (2005) highlights the significance of viewing current events in the context of the history of AIDS activism in the first decade of the epidemic. TAC cemented the message that poor citizens have a right to health and that public provision of healthcare and treatment for people with HIV and AIDS was not an unreasonable expectation. The message was deafening and unrelenting, and neither the pharmaceutical industry nor government was able to ignore it.

HIV and AIDS denialism was not exclusive to South Africa: it was initially observed in the United States, during the era of the Reagan administration. It has then been seen in India, China, Russia and many other countries. In all of these countries it has pitted people with HIV against their governments because it has entrenched the prejudice and stigma surrounding HIV, together with people's fear of AIDS (Heywood: 2004). The denialism in itself causes the stigma. It makes it more difficult for people to disclose their HIV status to family and loved ones. It makes it difficult for people to seek help and go onto treatment that can save their lives. It also gives false hope to people living with HIV and AIDS by claiming that HIV is harmless and that AIDS can be cured.

AIDS denialism created space for the emergence of such charlatans as Mathias Rath and Zeblon Gwala. Matthias Rath, a controversial doctor (who obtained his medical degree in Germany), businessman, vitamin salesman, and founder of the Dr Rath Health Foundation, claimed that a program of nutritional supplements, including formulations he sold, could cure or treat diabetes, cardiovascular disease, cancer, and HIV and AIDS. The claims were unsupported by any reliable medical research, but they were endorsed by the Minister of Health. TAC instituted legal action against Rath and the national Minister of Health (for more on this case refer to Treatment Action Campaign v Dr Matthias Rath, Case No: 2807/05; March 2006).

Zeblon Gwala, a Durban-based traditional healer, similarly, was selling Ubhejane⁷ as an alternative to antiretroviral treatment, and he urged people not to mix Ubhejane with antiretroviral treatment, resulting in widespread confusion about the appropriate use of antiretroviral treatment and the merits of vitamins and other supplements. TAC's complaint about an advertisement for Ubhejane placed by Zeblon Gwala in Ilanga newspaper on 6 December 2007, which made medical claims that were unfounded (www.tac.org.za/community/node/2113), was upheld by the Advertising Standards Authority of South Africa.

⁷Ubhejani is a fake AIDS cure to people with HIV with claims that it reversed the effects of HIV and AIDS

While stigma refers to an attitude or belief, discrimination is the behaviors that result from those attitudes or beliefs. HIV discrimination is the act of treating people living with HIV differently than those without HIV. The back ground of HIV was that of a government that did not want to give HIV treatment to people who were HIV positive. This was denying their existence (Division of HIV/AIDS Prevention: 2019).

TAC's struggles for access to antiretroviral treatment (ARVs) resulted in many life-saving interventions, including the implementation of country-wide mother-to-child transmission prevention and antiretroviral treatment programmes ([mackcenter.berkeley.edu/assets/files/articles/NGO South Africa TAC1](http://mackcenter.berkeley.edu/assets/files/articles/NGO_South_Africa_TAC1)). TAC's successes and changes to HIV and AIDS politics resulted in the organisation working in a fundamentally different political environment to that of 2000 – 2007. TAC has gone from a conflict-prone relationship with the Mbeki-administration, to improved working relations with Minister of Health Aaron Motsoaledi; it has witnessed people living with HIV shifting from fighting for survival to receiving ARV treatment, which is now a major component of the South Africa HIV and TB policy. These changes resulted in 1.2 million people receiving treatment in 2011 (Dubula: 2011).

How TAC managed to build branches to organise for treatment

TAC set up its first offices in Johannesburg, Cape Town and Durban in 1999. But branches were quickly established in cities, townships and rural areas across the country. TAC was mostly made up of volunteers, many unemployed with no income and no employment, who could give up their time and avail themselves to assist the organisation in doing its work. Volunteers were recruited from schools, factories, unions, churches, clinics and shebeens⁸. They were educated about the politics of HIV and AIDS and treatment literacy. TAC educated members on the importance of scientific and independent regulation of medicines and the functions of the Medicines Control Council (MCC). The role of patents, globalisation, compulsory licences, multinational corporations, the World Trade Organisation (WTO) and access to medicines remained an ongoing education process for all TAC activists and leaders (TAC: 2008).

Organising started at branch level and it was not always about big marches but about identifying small and local challenges where you could make and feel the impact. Branch members operated in their own communities, educating others on HIV science and establishing adherence clubs and support groups. TAC's goal was for campaigns to be devised and implemented with critical input from branches. TAC believed that campaigns can only become genuinely sustainable if they were driven by branches with local knowledge and expertise. The best way to sustain branches was to make sure that they are empowered, active and involved. They mobilised to become agents for positive social change in their communities. This model of social mobilisation and organisation was adopted from the struggle against apartheid. In 2010 TAC had more than 10 000 members in six provinces (Fighting for our lives: 2010).

⁸ (in South Africa) a shebeen is referred to as an informal licensed drinking place in a township

Active TAC branches have to perform a range of inter-related functions to be called a branch.

- The first thing is for the branch to start with a core group of people. This core group would be critical to the growth of the branch and should receive extensive training.
- The branch needs to decide to meet frequently at a regular time and place.
- As part of the induction process people will be educated on the history of the organisation, the aims and objectives of the organisation and receive Treatment Literacy training and learn to understand the campaigns and the work of the organisation.
- The branch must invite an experienced TAC member to attend the first branch meeting to answer questions and give an overview of TAC. Guest speakers from TAC should regularly visit the branch to discuss aspects of TAC's work.
- Once the core branch members have familiarised themselves with TAC, it is time for the branch to grow.
- The branch should advertise itself, display posters and make announcements at schools, clinics, churches and shops. Utilise the media to announce the new branch.
- Branch members should always take note of new people at meetings, protests or marches. Get their personal information. Perhaps they will be interested in joining the branch.
- The branch must make sure one of TAC's Treatment Literacy Practitioners (TLPs) or peer-educators is involved in the branch. Much of the branch work will rely on information from TLPs who are engaged with the TAC office and directly with issues on the ground.

In general the branches must be able to do research about relevant issues related to their communities on a regular basis because this will inform the campaign that needs to be taken up. Ongoing internal education must take place as often as the branch meets and this include Treatment literacy and political education. The branch must implement TAC Campaigns: Advocacy, Public Awareness and mobilisation. The branch must build local partnerships and alliances related to TAC campaigns. Lastly they have to monitor and support health service in their communities and establish community support groups (Organising in our lives: 2012).

In addition to addressing the health implications of HIV and AIDS, TAC also recognised the broader social and political implications of the disease at every level of society. Consequently, the organisation not only prioritised access to prevention, treatment and care, but also gender inequality, poverty, migrant labour and sexual myths and other such issues exacerbating vulnerability to HIV and AIDS within communities. As Achmat (The New Yorker: 2003) observes, personal, family, local community, provincial, national and international relations are all affected by considerations of whether people have access to prevention, care, and treatment and their exposure to the risks of HIV transmission. TAC's advocacy and

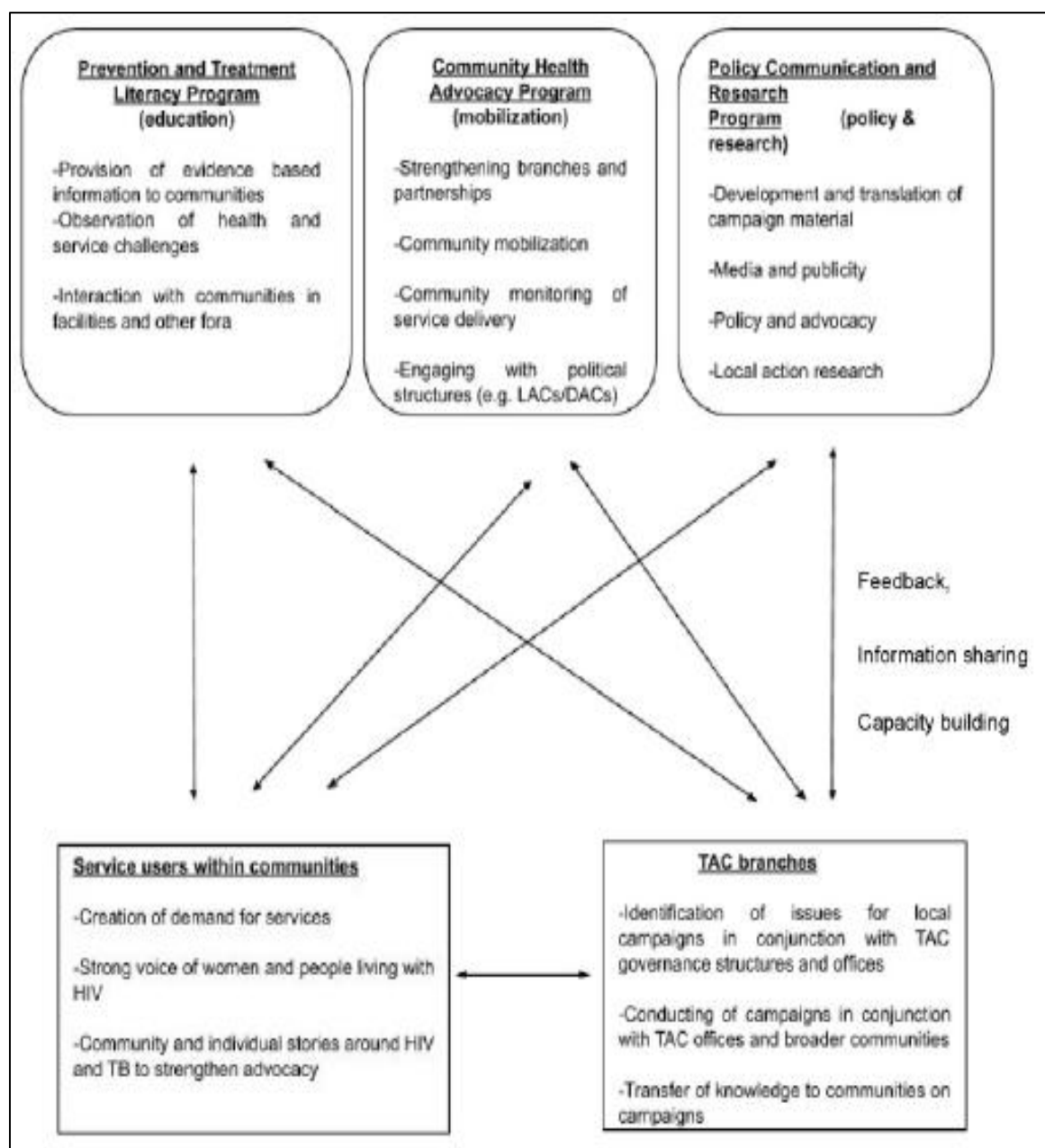
mobilisation efforts served to shift the HIV and AIDS debate from a political and policy one to human rights; this enabled the organisation to utilize the human rights mechanism established by the government to force its hand on the ARV issue (London: 2006; 12). TAC's intention was – through a mixture of protest, mobilization, and litigation – to popularize and enforce 'the right of access to treatment' (Heywood: 2009).

TAC activities were organised into 3 cross-cutting, and inter-related, programmes, namely: Prevention and Treatment Literacy (PTL), Community Health Advocacy (CHA) and Policy, Communication and Research (PCR)

1. The PTL programme's core focus was to provide evidence-based information to communities, transfer knowledge and ensure communities understood the science and the politics of HIV and AIDS and how it impacted on their lives; at the same time people were recruited to join the TAC branches and fight for access to treatment in the public health facilities. The programme encouraged HIV-positive people to disclose their HIV status in order to break the stigma surrounding HIV and AIDS and to humanise and put a face to HIV and AIDS. Communities were educated about the benefits of HIV and AIDS treatment and all this provided hope to the people because they began to understand that being HIV-positive or having AIDS did not have to be a death sentence but that you can live if you have access to HIV and AIDS treatment. This was at a time when poor South Africans could not afford medicine and had no access to HIV and AIDS treatment (www.tac.org.za/about_us).
2. The Community Health Advocacy Programme (CHA) was deemed essential in view of the continuing challenges impeding the public health system's ability to efficiently act in response to the HIV and AIDS and Tuberculosis epidemics, which were fuelling morbidity and mortality. The challenges included budgetary, logistic and related constraints, healthcare personnel and management deficiencies and exaggerated inequities between public and private healthcare facilities and services. Close monitoring, responsive action and strong advocacy were identified as necessary to address these challenges. This was done through community mobilisation, setting up of new and strengthening of existing TAC branches, forging and building local partnerships and engaging with local community and political structures. The programme also collected people's personal stories of HIV and AIDS to strengthen advocacy campaigns while monitoring service delivery.
3. The Policy, Communication and Research (PCR) programme sought to ensure that TAC's activities, campaigns, programmes, communications and policy positions were informed by best practice and evidence-based research. At the same time, this programme informed TAC members, stakeholders, government and the public about TAC's policy priorities, typically by means of

knowledge materials produced by the organisation. PCR's internal communications helped to coordinate and inform TAC's responses to important developments in HIV and AIDS and TB. PCR's external communications informed partners, the State, the media and the public about TAC's policy positions and campaigns (TAC Annual report: 2013/14).

Figure 4: Explains the links and synergies between programmes and branches of TAC



TAC TL programme

Why Treatment Literacy? Understanding the problem

The TAC Prevention and Treatment Literacy (PTL) Programme in part seeks to address the lack of scientific and evidence based knowledge on HIV and AIDS and TB prevention, treatment and care within and amongst the South African general public. Several factors contribute to this problem including:

- Inadequate access to public health care and information;
- Poor quality public information, including HIV prevention and treatment information;
- Lack of coordinated health information which leads to mixed messaging;
- A patriarchal culture that disempowers women, pointing to the need to draw on feminist theory to strengthen women's agency and enhance their ability to make sound health decisions;
- A crisis in masculinity which leads to men not taking appropriate care of their health;
- Poor implementation of the National HIV/AIDS, TB and STI Strategic Plan for South Africa (NSP 2012-2016)⁹;
- Inadequate access to public healthcare and information;
- High rates of unemployment and informal employment; and
- An inadequately resourced public healthcare system.

This programme, which commenced in 2003 when ARVs were due to be introduced into South Africa's public healthcare system, was designed to assist with the dissemination of ARV-related information, including their benefits, side effects, and need for strict adherence as well as other important information pertaining to health and patient's rights.

When TAC introduced their Treatment Literacy (TL) programme to communities it gave people hope, access to information, understanding about the disease, it empowered those infected and affected and raised community and self-awareness about HIV and AIDS and it inspired and motivated people. While TAC was educating communities and raised awareness it also recruited people to join the campaign and collectively struggle for access to treatment, especially at a time when Antiretroviral Treatment (ART) was not available in the public health sector.

Treatment can only be effective and sustainable if people understand the science of their illness, including how HIV progresses to AIDS, how various treatments work and what they can do to protect their health. Thus, the Treatment Literacy Programme endeavours to capacitate key actors in the health system and people living with HIV and AIDS in order to create awareness and demand for ARVs, spread treatment knowledge to reduce adherence problems and empower people living with HIV and AIDS about treatment options. The TL Programme builds leadership by developing the skills of Treatment Literacy Practitioners

⁹National Strategic Plan on HIV/AIDS, TB, STIs: 20012-20016. (<http://www.sanac.org.za>)

(TLPs) who work at the district and branch level in each of the provinces in which TAC operates. TLPs adopt local clinics and monitor and report on the quality of the services provided. Working through the provincial and district offices, the data collected then informs national and provincial advocacy efforts. At the time many TLPs were living with AIDS, and they worked daily to educate and mobilise their communities to prevent new infections, support government and civil society prevention and treatment efforts, and where necessary, organise to hold government accountable. The TL programme has demonstrated its ability to provide people with the skills necessary to secure employment in the health sector. In 2005, 31 TLPs have found employment in health care facilities and HIV and AIDS programmes. Previously trained TAC members now serve as community resources and enable the organisation to spread treatment literacy education to supportive civil society members and health professionals. In so doing, education leads to advocacy as TAC maintains the momentum for people to demand access to ARVs and to monitor and maintain pressure for quality treatment. In 2005, the TL programme has trained more than 6000 community activists. (TAC annual report: 2005).

INFORMAL AND NON-FORMAL LEARNING

A theoretical framework is provided in this section and it aims to provide a framework with which to analyse the men and women's learning as individuals in TAC TL programme by drawing on perspectives within the field of adult education.

Learning in a collective through dialogue and action

Paulo Freire's (1985) theory is used to describe and analyse learning in my study. He holds that the issue of literacy and power does not begin and end with the process of learning how to read and write. Instead, it begins with the understanding that one's existence is part of a historically constructed relationship of power (Freire: 1985). Popular education is different from formal education (in schools, for example) in that it is a process which aims to empower people who feel marginalized socially, economically and politically. It enables them to take control of their own learning and to effect social change. Currently, it forms part of adult education which has been described as 'an option for the poor' or 'education for critical consciousness. Literacy is part of the process of becoming self critical about the historically constructed nature of one's experience.

There is no such thing as a neutral education process. Education either functions as an instrument which is used to facilitate the integration of generations into the logic of the present system and bring about conformity to it, or it becomes the practice of freedom, the means by which men and women deal critically with reality and discover how to participate in the transformation of their world.

Freire (1970) views the aim of learning as being to change the status quo and aim to correct political and social inequalities that limit or hamper a learner's development (Fenwick: 2001; 39 – 46). Foley (1999) emphasizes the importance of “developing an understanding of learning in popular struggle” (1999; 140). “ ... incidental learning which occurs as people live, work and engage in social action; informal education and learning in which people teach and learn from each other naturally and socially in workplaces, families, community organisations and social action” (Foley: 1999; 6-7).

Often in social movements, like TAC, adult education practices which include experiential learning, respect and reflection are used to improve people's understanding of the problems and issues faced by the group in an attempt to develop an understanding of said challenges and through this process to direct efforts towards confronting and changing the group's circumstances. Radical adult education plays a key role in getting a group of people to collectively understand and act on the issues underlying their socio-economic and cultural situation. By helping activists increase their understanding of centralised power and develop their political skills, Adult Education, then, can also contribute to social action (Newman: 1995; 255).

Learning as Individuals: Perspective Transformation

Jack Mezirow's (1994; 222) contribution, on transformative learning is important for my thesis. He described an individual's critical reflection on experience and how they learn from it. Mezirow (1991; 1994) further stresses that learning is central in the way that an individual sees the world, with learning being a unique experience, which makes necessary development of the individual. However, these men and women, as adult learners, work within the limits of their current way of viewing, sense-making and understanding the world, which they acquire through prior learning and experience, which then becomes the foundation upon which any new learning is recognized.

Mezirow (1991; 247) stressed the need to produce a social framework, which he posits increases learning because the individual and the belief they have about experiences can then be brought to their awareness for recognition, acknowledged and sharing with others. This does not imply that the individual's assumptions are confirmed, but rather that the individual is validated as a person even as they crucially engage with their problematic assumptions. The context within which learning occurs is also an important factor for the learner, who remembers it when interpreting what is learnt, since it is almost impossible to separate out the elements of a social situation.

¹⁰*Gramsci, Freire, and Adult Education: Possibilities for Transformative Action*, by Peter Mayo, Macmillan, 1999, [ISBN 1-85649-614-7](#), pg 5

According to the Transformative Learning Theory, there are three dimensions (psychological, convictional and behavioral) involved in "perspective transformation": Psychological where individuals or learners change their perspective or understanding of themselves and for real learning to take place individuals must be able to think autonomously. Convictional, when transformation of the belief system takes place such as personal values and assumptions instead of going along with the status quo, individuals or learners shift their cognitions based on their personal experience. Behavioral, when individuals or learners alter their lifestyle. For example, they might change some habits based on the information they received. The learning experience transforms their behavior and influences their actions.

Contrast and Similarities of Paulo Freire and Jack Mezirow

Jack Mezirow and Paulo Freire are both scholars and authors who have closely examined and explored adult learning methodologies, theories and best practices. Mezirow authored the popular, *Transformative Learning: Theory to Practice* and Freire writes about "education for liberation". Freire's main message focused on the importance of learning as a way to challenge assumptions and fundamental beliefs based on one's history and culture.

Freire's (1970) emancipatory views on education as a means for empowerment have had an influence on social movements and his work updated the concept of popular education and placed it in context with current theories and practices of education, laying the foundation for what is now called critical pedagogy. Freire regards learning as purpose based on a rediscovery of power such that the more critically aware learners become the more they are able to transform society and subsequently their own reality. Freire believed that by the act of transformation, society is transformed. Jack Mezirow (1994) described the transformational learning theory as being "constructivist, an orientation which holds that the way learners interpret and reinterpret their sense experience is, central to making meaning and hence learning" (222).

TAC started a Treatment Literacy Programme to educate communities and people that live with HIV and AIDS and to highlight the challenges of AIDS in the country. TAC members were responsible for mobilising communities and getting people infected and affected by HIV and AIDS to stand up and do something about their situation. According to Mezirow (1996) transformative learning offers a theory that is partly a developmental process, but more as "learning is understood as the process of using a prior interpretation to construe a new or revised interpretation of the meaning of one's experience in order to guide future action" (Mezirow: 1996; 162).

Both Freire (1985) and Mezirow (1991; 1994) take into consideration the importance of the social context in which learning of an individual takes place and both perspectives focuses on cultural and historical influences and how thus impacts on the way individuals understands, exist and engage in their world. The difference is that Mezirow's work on transformative learning focuses on personal development while Paulo Freire work on transformational learning focuses on social change.

Learning as a Community: Situated Learning

For Lave and Wenger (1991) learning is a social and shared practice, which takes place through the performance of actions. Learning is therefore a collective process. The women and men in TAC learn through discussion and actions, for example, while they were learning about HIV and treatment they were also fighting for access to HIV treatment.

Situated learning theory argues that learning occurs best when it takes place in the context in which it is applied. Situated learning "takes as its focus the relationship between learning and the social situation in which it occurs". According to Lave & Wenger (1991; 98), learning is not necessarily the major purpose of a group but is entrenched in the context and practice of the group. Lave and Wenger's views are important to this research because they forefront learning in terms of sharing and participation within a group, which they term 'a Community of Practice'.

Learning happens through observation, giving and understanding within the group. It is both obvious and implicit and is rooted in the rules of the group, embodied by members and displayed in terms of shared main beliefs and principles. Learning is a means to improve the value of group actions; knowledge and skills acquired are seen as context dependent and not easily exchangeable. The notion of 'Community of Practice' and Lave and Wenger's related concepts therefore have important implications for how and what information women and men access in relation to their health rights as they mainly rely on members of the group for information to sustain their learning: therefore, if the context does not allow for new learning to happen, then current practices may not change.

Defining informal and non-formal learning

Newman(1995; 248) advances that informal learning occurs when people become conscious of the potential for learning in their actions and make a decision to learn from those experiences, whereas formal learning is methodical and structured, non-formal learning is organized but not in a recognisable or particularly structured educational context/format. Non-formal learning includes various structured learning situations which do not either have the level of curriculum, syllabus, accreditation and certification associated with 'formal learning', but have more structure than that associated with 'informal learning', which typically take place naturally and spontaneously as part of other activities.

Traditionally, both informal and non-formal education has played a key role in building the capacity of social movements through inter alia: training sessions, awareness-raising discussions and debates on issues pertinent to the aims and objectives of the social movement concerned. This happens through discussion of experiences, looking for answers to issues and reporting back to the group. This is a critical means of access to new and useful knowledge by the group. Although inequalities in knowledge and experience exist, these groups are not necessarily run by professionals (Newman: 1995; 248).

Learning in Social Movements like Treatment Action Campaign

This section discusses the different forms of learning that have played a role in social movements like incidental learning, formal and non-formal learning, the creation of knowledge, how learning occurs and happens in different ways, as outlined below.

Theorists like Newman (1995) define social movements as a social shared action in which a group of people are brought collectively by shared history, a shared social class, a shared neighbourhood, a shared concern or the common partisanship of an organization united together to learn and take action on their social, political, cultural and economic surroundings in order to gain more control over their own lives (Newman: 1995; 247).

Others like Drew Forrest (2003) define movements as a very loose group of left-learning, community based social movements that vary in focus, size and influence and are mostly minuscule. What unites them is a shared aspiration to help the poor and oppressed, and, in varying degrees, a common dislike to hierarchies and bureaucracy, the profit motive, the unfettered market and corporate power (Drew Forrest: 2003; 8-10).

It may be argued that the most powerful learning that takes place in social movements is incidental learning which takes place during action, and it may only be in retrospect that we recognise that learning has taken place. Incidental learning happens when people are engaged in group activities and through interaction with others, individuals create new ways of thinking about themselves, how they relate to others in the group and to the environment in which they operate. For example, people in community organizations and community development projects learn to write submissions, run an office, canvass community opinion, and lobby public servants in the course of conducting their community activities (Newman: 1995; 247).

There is relatively little formal structure which often hides the embedded power of particular individuals, especially ones with charismatic personalities. Methods of learning include sharing of experiences and feelings, facilitation of meetings, encouraging participation; sharing of tasks, skills and experiences and learning through training and action. From this one can conclude that the type of learning that is confirmed is learning when someone acquires information in social movements is learning which leads to knowledge which enables people, as Newman (1995) states, “to act on their learning as a group” (Newman: 1995; 246-247). Social movements can therefore be viewed as both sites of learning as well as sources of new and useful knowledge (Newman: 1995; 248).

CHAPTER 3: RESEARCH DESIGN AND METHODS

“My family understands now what is HIV because of information I got from TAC”. (Rabecca: 2015; interview)

This chapter provides the research design and methods that guided the research process by outlining procedures, processes and analyses used to answer the research question. I discuss how I did the data collection, sampling, data collection approach, data collection tool, data analysis, data verification, ethics and my limitations.

RESEARCH DESIGN

A qualitative, exploratory approach has been adopted for this study. As stated by De Vos (1998), a research design is a strategic framework for undertaking research: a qualitative approach is adopted when one seeks to understand and explore a phenomenon more deeply. Qualitative research (Maykut and Morehouse: 1994; 19) is research which attempts to increase our understanding of why things are the way they are and why people act the way they do. The qualitative research method is therefore appropriate as the aim of this qualitative study is to examine human behaviour and the social world people inhabit.

I used interviews and document analysis to gather information for this study.

SCOPE OF MY STUDY

The scale of this research was restricted to six participants, who come from low income groups in the Western Cape, and went through the Treatment Action Campaign’s (TAC) Treatment Literacy (TL) programme. The study also explored the participants awareness and understanding of their experiences, what attracted them to TAC, how they learned, what they learned, how did it changed their practices and what their general experience was the social movement’s literacy programme. The study used quotes to give voice to these participants. The study is not an evaluation of the TAC TL programme.

My responsibility as the researcher was to understand the findings from participants’ views of how they became aware and practiced before participating in the literacy programme and what learning happened during their experiences and after participating in the literacy programme and whether or not the programme made a difference in their lives. I hope that the research findings will provide a window into how participants’ learned informally and non-formally in their day-to-day activities to make sense of their work, their lives and their worlds.

SAMPLING AND SELECTION OF PARTICIPANTS

A purposive sampling which I found suitable for my study design was used. The sample was drawn from people with whom the researcher was familiar; therefore, the researcher chose 6 participants who were accessible and able to provide diverse perspectives as opposed to a random sample, as outlined by Miles

and Huberman (1994). Participants were familiar to me because we have worked in some way or the other within the organisation. They were accessible because I knew that they went through the TAC TL programme.

I held a meeting with participants to introduce the study and to discuss and clarify the format and criteria. As the researcher I identified participants that I was familiar with, who had been through the TAC TL programme. The selected participants were divided according to age, race, gender, HIV and AIDS-status (some participants were infected while others were affected by the disease) and came from different backgrounds and communities thereby representing a range of TAC members from different learning contexts and communities.

Half of the participants are still actively involved with TAC and the involvement of others has declined, while some participants no longer have any involvement with the organization. While all of the participants were open about their HIV status (whether HIV positive or negative), the focus of the study is not on participants' HIV status, so this is not discussed.

DATA COLLECTION

As noted, this is an explorative qualitative study. Permission was sought from the participants before the interviews started and they freely provided their consent before the interview was conducted¹¹. The data collection approach selected was six face-to-face, in-depth interviews using an interview schedule¹². In preparation for the interviews, I compiled an interview schedule with guiding questions to assist me in the process of data collection¹³. Interviews were audio taped and I carefully transcribed it for later use. In preparation for the audio recorded interviews, as advocated by Yin (1994) several interview questions and secondary probes for eliciting more elaborated responses were developed and cautiously written up for later use in data analysis. As the researcher I was able to seek further clarification and investigate where necessary and observed for non-verbal signs to accurately report on the responses. This was done to gain interpretations of participants' feelings about their learning and their practice, their perception of the role of experience in learning (Maykut and Morehouse: 1994; 19). This process allowed the participants to respond without restraint using their own expression and words, explain their views, and instigate and maintain a conversation with the researcher. As the researcher this approach enabled me to check for patterns in the data and attain direct information, which was used to build up and expand theory and content pertaining to participants' stories. Each interview lasted between thirty and sixty minutes.

I also used documentary evidence, i.e. TAC TL publications, TAC literature; newspaper reports, internal TAC policy documents, written reports and analysis of documents, and others were consulted as

¹¹ Appendix 3, consent form

¹² Appendix 1, interview schedule

¹³ Appendix 2, interview guide

additional, secondary sources of information, which proved invaluable to the research (Hansen: 1995) and (Hoepfl: 1994). The sample of the documentary evidence was not chosen in any particular format but rather what was accessible at the time.

DATA ANALYSIS

Qualitative data analysis as defined by Bogdan and Biklen (1982; 145) is "working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what...[to] tell others". According to Patton (1990), qualitative researchers tend to use inductive analysis of data, meaning that the critical themes emerge out of the data. Qualitative analysis requires some creativity, for the challenge is to place the raw data into logical, meaningful categories; to examine them in a holistic fashion; and to find a way to communicate this interpretation to others.

The analysis began with identification of the themes emerging from the data, a process sometimes referred to as "open coding" (Strauss and Corbin: 1990). During open coding, I identified and named the conceptual categories into which the phenomena observed were grouped. The goal was to create descriptive, multi-dimensional categories which formed a preliminary framework for analysis. Words, phrases or events that appeared to be similar were grouped into the same category. These categories may be gradually modified or replaced during the subsequent stages of analysis that follow. For example, one of the conceptual categories was participants' motivation for becoming part of TAC. I read through each of the participant transcripts to become familiar with the content, looking for patterns in the data. When something interesting or out of the ordinary was detected, I made a note about the information and colour coded the transcripts according to categories which emerged from the participants' stories. Then, using the original guiding questions as a framework to provide initial categories and conceptual names, the data was matched to categories accordingly. Using De Vos (1998) advice to make sense of my data and to analyse and interpret it I transcribed all the data from the interviews and analysed it manually, together with my notes

Thematic content analysis was used to interpret the data as advocated by Maykut and Morehouse (1994; 19). This is a procedure for the categorisation of information to enable the researcher to classify or summarise data. The content analysis was done to provide a descriptive account of the data, i.e. this is what participants said. Since this is an interpretive research, the data analysis was also concerned with what was meant, or what was inferred or implied by what the participants said. The data was transcribed verbatim. This enabled me to develop and refine themes and sub-themes that I put onto a spreadsheet, for example, when the participants explained about what they learnt, they answered that they learnt about reading, one participant learnt about their rights and the another participant learnt about the science of HIV and AIDS, this information was put into one category.

Key themes and sub-themes emerging from the data which linked with my research questions were identified:

Participants levels of awareness, understanding and practice of health rights

- Their motivation for becoming part of TAC
- Participants perception of TACs TL programme
- How participants learned
- What did participants learn?

Factors within TAC which enable awareness, understanding and practice

- Participants experience of TAC and their understanding of HIV and AIDS
- Participants community experience

Barriers to awareness and understanding of TACs TL programme

- Did TAC and its TL programme inspire participants?

I present the findings as themes which are a reflection of participant's responses in line with Maykut and Morehouse (1994).

Validity, Reliability and Credibility

In qualitative research these terms are interpreted differently to quantitative research and I used Lincoln and Guba's (1985) definition of trustworthiness to test validity and reliability. They argue that sustaining the trustworthiness of a research report depends on ensuring the soundness (i.e. validity and reliability) of the issues. Credibility is about confidence in the 'truth' of the findings. According to Guba and Lincoln (1985), research is regarded as credible when representing accurate descriptions or interpretations of the participants' experiences. I secured credibility by providing copies of the transcripts to the participants to check and for comment before analysing the data. The idea of discovering truth through measures of reliability and validity is replaced by the idea of trustworthiness (Mishler: 2000), which is "defensible" (Johnson: 1997; 282) and establishes confidence in the findings (Lincoln & Guba: 1985). Lincoln and Guba posit that trustworthiness of a research study is important to evaluating its worth.

In terms of trustworthiness, I was consistent in the data gathering process and asked the same questions guided by the interview schedule of each participant. I cross-checked the interview transcriptions with the participants as well as checking for consistency in the data when analysing the data. I interrogated my position as a TAC manager throughout the research process. Debriefing sessions were held between researcher and supervisor throughout the research process to ensure that I was collecting, coding and analysing the data as truthfully as possible.

Positionality of the researcher

A considerable amount of literature discusses the insider-researcher's journey in terms of highlighting the dilemmas and challenges in the research process (Al-Makhamreh & Lewando-Hundt: 2008; Labaree: 2002; Paechter: 2013; Rogers: 2012 & Taylor: 2011). These researchers suggest that the experiences of individual researchers differ according to the nature of their research, the familiarity of the investigator with the participants, and the context under investigation.

As the researcher, I also worked in TAC as the national campaigns manager at the time when the research was done and am aware that my role in the organisation could have influenced that data collection. I am conscious that I come with my own ethics and perceptions of adult learning. Therefore this research must be viewed through a constructivist lens as defined in Fenwick (2001) on the side of the researched, the researcher and the reader. Constructivism is a learning theory which explains how people might acquire knowledge and learn and therefore has direct application to education. The theory suggests that humans construct knowledge and meaning from their experiences (University of Sydney: 2002-2012). Consequently, the analysis of my findings will be a review and critique of the participants' (and my own) responses, levels of awareness and value statements, linked with theoretical perspectives located within an adult learning framework making up much of the focus of this particular research.

Ethical considerations

Capron (1989) says that any kind of research should be guided by the principles of respect for people, beneficence, and justice. He considers respect for people in the research context to consist of recognition of and respect for participants' rights, including the right to be informed about the study, the right to freely decide whether or not to participate in a study, and the right to withdraw at any time without penalty. I followed these principles and requested informed consent for the research from this study's participants before commencing the research. They were talked through the research process and provided with information about the study, its purpose, security of information, confidentiality of identity and protection of names of others and organisations and their rights as participants, in particular their right to withdraw from the research at any stage (Seale: 1999 & Creswell: 2008; 157). A letter of information outlining the research topic, purpose, and consent was read, dated and signed by all participants (Leedy & Ormrod: 2001; 108)¹⁴.

The names of participants and places used in the analysis and discussions of the findings are pseudonyms. Following Patton (1990; 356), to maintain anonymity I endeavoured not to make information public that would harm people's reputations therefore I did not link any interview quotes that would connect to the participants. In that way I maintained confidentiality and anonymity. Participants were also assured that the transcriptions were undertaken solely by the researcher and were made available only to the

¹⁴Appendix 3, participant signed form

researcher's academic supervisor when requested. All data gathered was treated as confidential. In the context of this research, ethical clearance was obtained from the University of Cape Town prior to the commencement of data collection.

Methodological Challenges

Although I diligently followed the procedure of the research design one challenge arose. One of the Xhosa speaking participants, who had initially consented to be interviewed in English did not express himself well in English at times; however, the researcher did not, at the time of the interview, have recourse to a Xhosa interpreter and translator (for the transcription), the quality of the participant's response may not be as strong as it may have been otherwise. I know he would have answered some of the questions in greater detail if he could speak English fluently; this was made especially apparent when the interview was being transcribed.

SUMMARY OF THE CHAPTER

In Chapter 3, the research design and the research method of my research study was presented. I outlined the sampling procedure, data collection process and data analysis which assisted me in answering the research question of this study. The research methods used served to justly and truthfully describe the crucial aspects of the study so that other researchers can test the transferability of the research embarked upon in this study.

Chapter 4 presents the research findings

CHAPTER 4 - RESEARCH FINDINGS

“It was such a high level type politics, it’s a combination of HIV science and medicine, it’s the law, its global governance, its economics, its local governance, it’s how municipalities functions, budgeting, it was complex, it was like studying things that people would study in four different modules but we would study all of that in one”. (Violets: 2015; interview)

INTRODUCTION

The findings of the research study using thematic analysis of the study are being represented in the chapter. The study explored the experience of six people who participated in a Treatment Literacy programme implemented by the Treatment Action Campaign in the Western Cape in the period 2001 to 2009. The study examined participants’ awareness and understanding of their (learning) experience within TACs TL programme and addressed: What attracted participants to TAC; how and what they learned; their perception of the learning process; and whether it had any bearing on their perception of the TL programme.

Quotes from the interview transcripts are used for the following purposes:

- i. To demonstrate themes emerging from the data and show the breadth of participant responses as they relate to a particular theme.
- ii. To help give proof for analysis and interpretation in order to strengthen the credibility of the overall findings.
- iii. To assist and enable the voices of the participants to come through in the findings.

I acknowledge that through this study the participants’ voices have been filtered through my interpretation of them as the researcher and through their own interpretation of reality and how they chose to construct meaning during the interview process.

PARTICIPANTS’ PROFILES, LIFE EXPERIENCES AND SOCIO-ECONOMIC CONTEXT

This part provides a description of who the participants were which includes participants’ age, where they were born, where they live, what language they speak, when they joined TAC, and whether they currently employed.

Participants’ Profiles

The following provides descriptions of three women and three men included in the sample as individuals. These six participants all come from lower income groups in the Western Cape. Two male participants

and one female participant are still actively involved in TAC, whilst the other two female participants are supporters of TAC, joining activities when they can. The one male participant is not involved in TAC anymore. Participants' profiles and life experiences indicate that there were differences and similarities that exist amongst the men and women who are diverse in age, race and levels of poverty and life experiences¹⁵. Below I present the profile of three women and three men that participated on the study.

Figure 5: Participants' profiles

Participants	Nomvula	Violet	Richard	Mofokeng	Timothy	Rabeca
Gender	Female	Female	Male	Male	Male	Female
Age	46	37	52	49	51	52
Race¹⁶	Black	Black	Coloured	Black	Coloured	Coloured
Born	Paarl	George	Klein Karoo	Manenberg	Eastern Cape	Prieska
Home Language	Understand and speaks English but Home language is Xhosa	Understand and speaks English but Home language is Xhosa	Understand and speaks English and Afrikaans but Home language is English	Understand and speaks English but Home language is Xhosa	Understand and speaks English but Home language is Afrikaans	Understand and speaks English but Home language is Afrikaans
Learning Background	Did not complete High School	Completed High School and currently studying	Completed High School	Completed High School	Did not complete High School	Did not complete High School
Employment Status	Trainer	Lecturer	Unemployed	Community Worker	Factory Worker	Community Worker
Joined TAC	2001	2001	2002	2005	2001	2005

Figure 5 indicates that the three men and three women's ages range from late thirties to early fifties. For the majority of the men and the women English is not their home language. Literacy levels of one male and one female are at a functional literacy level; two of the men and one woman completed Grade 12. One of the females has a tertiary qualification and continues to advance her studies. The relationship status of

¹⁵The names of people and places used in the profile and life experiences are pseudonyms as suggested by Patton (1990; 356) to maintain anonymity.

¹⁶Acknowledging that the terms Black and Coloured are problematic and that there are different understanding of the terms, for the purposes of this thesis, the terms Black refers to black South Africans who are descended from isiXhosa cultures and Coloured refers to people who are of mixed origin and speak English or Afrikaans (Ismail, 2006).

the participants varied, with some married, others single, some divorced and others widowed. All of the participants have children, and some of them also have grandchildren.

In terms of habitation, although all of the participants are currently living in brick houses, this was not the case for many of them growing up. Four of the participants come from rural areas in the Western Cape and one participant came from an urban area in the Western Cape. The one participant that originated from a rural Eastern Cape moved to a rural area in the Western Cape but currently resides in an urban area in the Western Cape.

Of the six participants, only one woman and one man were directly involved with health-related programmes in their communities before becoming involved with TAC; the rest of the participants had worked in a shop, a bank, hair salon, hardware store and a community with youth soccer programme. Almost none of the participants were actively involved in political activities during the Apartheid era with the exception of one male participant.

Brief background of the participants

Nomvula is a 46 year old woman from the Paarl district in the Western Cape. She is a Black Xhosa-speaking woman who had to leave school early because of the high rate of unemployment and poverty in the area. Before she became involved with TAC she was employed on a part-time basis as a hairdresser and was also doing a bit of home-based care work in the community.

Violet is a 37 year old, black, Xhosa-speaking female who was born in George and relocated to Khayelitsha on the Cape Flats. In 1997 she completed high school before studying for a diploma in Human Resource Management, which she acquired in 2000. From 2000-2001 she did odd jobs, including a stint working at Shoprite. She is currently advancing her studies at a Higher Learning Institution.

Richard is a 52 year old male who was born and raised in Klein Karoo. He is an English speaking, coloured male. He spent a lot of his time with family in Cape Town and at one stage of his life he was also living in Johannesburg. He comes from a family of twelve: ten brothers and two sisters. After completing high school he worked as a bank clerk.

Mofokeng is a 49 year old male who was born in the Free State and moved, at the age of two, to the Western Cape where he completed High School. He lived in Limpopo for a while before moving to Manenberg on the Cape Flats in Cape Town in 2004. He is a black, Xhosa speaking male who worked part-time at an electrical shop and assisted the community with soccer development before his involvement with TAC.

Timothy is a 51 year old male originally from the Eastern Cape. He is a coloured, Afrikaans-speaking male who had to leave school early to help his single mother provide for his three brothers and one sister. He was actively involved in a range of activities related to the struggle, which raised his literacy level.

Rabecca is a 52 year old, Afrikaans-speaking coloured female. Her family is originally from Prieska but she was born in Philippi on the Cape Flats. She did not complete school, dropping out in Grade 7. She comes from a family of ten children and she first came into contact with TAC when she asked one of TACs Treatment Literacy Practitioners a question while conducting HIV educational talks at a health facility in the Western Cape.

All the participants during this time period were living in the Western Cape, with the majority living within the City of Cape Town. All the participants come from poor, marginalised backgrounds and the majority have only held low-income jobs, with some acting as voluntary workers or holding down part-time employment at the time of the interviews. Although all of the participants could understand and speak English, this is the mother tongue of only one participant: others are first-language Afrikaans speakers and others first-language Xhosa speakers.

Most of the participants became involved with TAC in the early 2000s, with the exception of two participants who joined the organisation in 2005. Although none of the participants were asked to disclose their HIV and AIDS status, while being interviewed, all voluntarily did so in the course of being interviewed. All of the participants had some form of knowledge and understanding of HIV and AIDS at the time they came into contact with TAC; and all participants were either infected or affected by HIV and AIDS. Most of the participants were employed by TAC in one or another capacity at some stage. It should be noted that this research study did not investigate whether the TAC TL programme contributed to participants' openness about their HIV and AIDS status for which reason the HIV and AIDS status of participants is not disclosed.

The analysis of participants' profile makes it clear that TAC and its TL programme reached people of different genders, racial and geographic communities across the Western Cape.

LEVELS OF AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS

Participants' motivation for becoming part of TAC, their perception of the TAC TL programme, and the nature and substance of their learning are being explored in this section.

Their motivation for becoming part of TAC

The participants who joined TAC between 2001 and 2002 were motivated to do so at a time when access to treatment was not available in the public health. The motivation of two participants who joined TAC in 2005 was the desire for more information pertaining to the practical measures for accessing treatment

which had become publicly available: Violet turned to TAC as she needed help and desired more HIV and AIDS related information more generally. She recounts:

“I wanted help ...and then you are told there is an organization that helps - that fights for the rights of people living with HIV... (then that’s where you go)”. (Violet: 2015; interview).

Rabecca, after sitting through an educational session delivered by a TAC TL practitioner at a health facility in the Western Cape, approached the practitioner with questions on HIV and she was invited to join the TAC branch in her community. In Rabecca’s own words:

“I went to the hospital and that is where I met one of the treatment literacy people ... from TAC and I called her and I spoke to her”. (Rabecca: 2015; interview).

Nomvula was deeply affected by the loss of six friends to HIV and AIDS, which convinced her that “enough is enough,” she needed to know and understand more about HIV and AIDS. Nomvula says:

“I lost six of my best friends and that was a wake up (call). Something happened to me that made me change and t[hats] [w]hen I started off with TAC as a volunteer”. (Nomvula: 2014; interview).

Participants’ motivation for becoming a part of TAC differs from one individual to another. Some participants needed help with access to HIV treatment and looked to TAC for that help. Another participant was recruited by TACs leadership to become involved in the organization, with the purpose to recruit in specific geographical areas. One participant was diagnosed HIV positive and joined a support group. At the support group a TAC member recruited him formally to join the organisation. Another participant had a very low CD4 count and was at one of the health facilities when he was recruited to join TAC. At the time TAC was one of the organisations that provided a safe space for individuals living with HIV and AIDS including those affected with HIV and AIDS. Out of the six participants five approached TAC and one participant was approached by TAC.

Participants perception of TAC’s TL programme

The members of TAC managing or delivering training for the TL programme were themselves prior participants of the training. Their knowledge was supplemented by professional doctors, lawyers, psychosocial practitioners, HIV and AIDS activists among others – not only from South Africa and local organisations but as far afield as the United Kingdom, France and such organizations as i-Base¹⁷ and MSF. All of the topics addressed in the trainings were broken down into details with practical examples provided to facilitate intensive discussions. Reading materials were distributed to all participants during the training and most of the material was in English at the time. Reading was always promoted and assignments and group work constituted part of the TL training. Nomvula recalls:

¹⁷HIV i-Base is a treatment activist group. i-Base was formed in April 2000 by the former publications, editorial and meetings team from the AIDS Treatment Project, London.

“We used to go for training with the coordinators and people like doctors and people who are experienced from other countries. They [would] go into detail to explain what human anatomy is. Then they [would] make or show us practical examples or show us personal examples and give us materials, books to read and give us assignments or group work”. (Nomvula: 2014; interview)

According to Violet a lot of emphasis in the training was placed on activism, training was facilitated by activists fighting the HIV and AIDS struggle on the frontline. This inspired many participants and gave the training so much more meaning; coming face-to-face with the leadership of TAC made participants feel that they also had the potential to make a difference. Violet further explained that she was greatly motivated both by the reality of South Africa’s status as a developing country in the early 2000s and the fact that many HIV and AIDS issues still needed to be advocated for with a government in denial about HIV and AIDS and providing poor people with access to treatment. She therefore perceived the TAC TL program as enlightening and empowering people while also recruiting members to join the campaign for access to treatment. In Violet’s own words:

“There was an infusion of activism because we were taught by activists themselves, whether they were doctors or lawyers, they were lawyer activists, they were doctor activists and then the pure activists like Zackie, Mark, Nathan, Nonkosi and Siphos... that combination allowed us to see that there is something that you can do, no matter how small and insignificant you think it is, it made everyone in the [training] room feel that there is something that you can do”. (Violet: 2015; interview)

Thus, in TAC and the TL programme specifically, informal learning occurred as participants became aware of the learning potential contained within their activities and they consciously decided to tap into and learn from the experiences in question.

Violet recalls that the TAC TL programme was popular within TAC, which was largely attributable to the fact that all TAC personnel had themselves undergone training. She goes on to say that TAC became popular or well-known by others working in the HIV and AIDS sector for this TL programme:

“I think it was popular education. Popular education is something that many movements have, the ANC has its own popular education...all movements have their own popular education, so treatment literacy became the popular education for TAC”. (Violet: 2014; interview)

Timothy was of the view that the knowledge and information shared at TL trainings empowered individuals, giving them confidence to return to their communities and knowledgeably engage them on HIV and AIDS-related issues. TL training participants were afforded the opportunity to maintain communication with TAC even after the training, in order to follow-up on and obtain additional information on any issues on which they needed clarity. Individuals who underwent the TAC trainings and workshops were thus strongly convinced about the benefits of the training, with some individuals of the opinion that the programme benefited them more. As Timothy asserts:

“Knowledge is power and you cannot go and inform, convince and persuade people to join up to understand if you yourself do not have full understanding. For me as an individual that was a pivotal part of TACs work because we could now go out and we could now educate our own volunteers first and foremost”. (Timothy: 2015; interview)

TAC appears to have achieved some of its objective of its TL programme, namely to empower individuals and communities to take control of their health by understanding HIV and AIDS prevention, treatment, and care and related social issues at the time. The TL program therefore successfully empowered, raised the awareness of and increased the confidence of participants while simultaneously inspiring and raising the awareness and understanding of the broader populace at a time of entrenched state denial on HIV and AIDS and the need for treatment.

How participants learned

The kind of learning affirmed in social movements is learning which leads to knowledge that enables people to act on their learning as a group (Newman: 1995). Social movements are thus simultaneously a site where new and useful knowledge is acquired and learning occurs (Newman: 1995; 248). The TAC affirms this learning approach. According to participants of the TAC TL programme, learning happens in two ways, namely informal and non-formal.

Participants recall that TAC's material was not restricted to printed manuals: the organisation also drew on cultural forms of knowledge such as songs, storytelling and drama to communicate and impart information to participants. The culture of reading was always promoted to broaden people's understanding of how the world works and the personal stories of HIV-infected participants or trainers brought another dimension to the learning process. People could draw on their personal experience and speak from their subjective perspective and experiences, which left an indelible impression on people. The best learning was the actual debates and discussions, the physical going to places, the engagements and the interactions with politicians, drug companies, the police and being at the forefront of the fight for access to treatment. According to Nomvula and Violet, it was the use of different training approaches and mediums and learning in action that enabled TAC to reach a wider audience, including in people who had low levels of literacy.

TAC communicated its message using every conceivable medium - songs, emails, newspapers, videos, television, newsletters, leaflets, posters, conferences, fact sheets and so forth. TAC did this to reach as wide an audience as possible, as many individuals within the organisation and the broader general public were not highly educated and thus could not read or easily understand science or health policy issues. In this way, TAC sought to reach everyone in society - urban and rural, rich and poor, black and white, young and old, infected or affected by HIV and AIDS. TAC created its own media content, which it disseminated using the media outlets above stated.

“Reading was promoted 100% in this programme...” (Nomvula: 2014; interview)

“...‘HIV in our lives’ it became a much more comprehensive booklet we could use for trainings, but even ‘HIV in our lives’ it was never technical we wanted it to be user friendly, like people in support groups could take and read over the year, if someone wants to read this chapter or this section they could read it...” (Violet: 2015; interview)

Mofokeng says that participants were learning through songs.

“There’s the songs that people actually translated to the treatment that is being used for people to understand”. (Mofokeng: 2015; interview)

TAC published a magazine called ‘Equal Treatment’ and a comprehensive training booklet called ‘HIV in our Lives’. These books were part of the material that was used and distributed during the TAC training. The unique thing about ‘Equal Treatment’ at the time was that it used real people and their pictures to tell their real stories about HIV and AIDS. Most of the time it would be individuals who were part of the organization. This would make the experience of participants’ real and learning experiences become meaningful. This was one of the strategies that TAC used to promote and encourage disclosure of people living with HIV to accept their HIV status. This way of learning was to inspire people and to bring people’s stories closer to home. This is about the personal being political and the feminists talk about this.

As a matter of principle all the stories in our material had to be real stories about real people. (Violet: 2015; interview)

The findings above show that TAC used a variety of methods and ways to communicate HIV and AIDS to the people, through informal ways of raising awareness and educating people about HIV and AIDS through reading, songs, emails, newspapers, videos, televisions, newsletters, leaflets, books, posters, wearing of the HIV t-shirt and actual debates about the subject matter. Incidental learning in TAC assumed the form of people being afforded the opportunity to voice their own concerns, to engage with one another, politicians and other state institutions and representative (public healthcare professionals, police, policy makers) and finally as a result of skills acquired in the course of being activists at the forefront of the struggle for access to treatment.

Non-formal learning

The TAC TL manual had a lot of information, which was broken down and simplified in the form of easy-to-read fact sheets that provided summarized information in plain and clear language for greater accessibility of the ideas contained in the manual. All TL material was also translated into the dominant local languages (in the Western Cape, Afrikaans and Xhosa). This means that non-formal learning is systematic and structured (Newman: 1995; 248).

Mofokeng, Richard and Rabbecca were part of a group that participated in a one-week long training which prepared them – as people who would be publicly representing TAC – to address all pertinent information pertaining to HIV and AIDS. All three participants asserted that this training substantially enhanced their understanding of HIV and AIDS, which prompted significant behavioural and attitudinal shifts in their lives. As Mofoken notes:

“My first Treatment Literacy training was... [in] Grabouw.¹⁸ Other TAC members also part[icipated in]...the training and the trainers made sure that everyone was informed. As a TAC member you are questioned about HIV in the community and [when you are informed] then you can answer the questions”. (Mofokeng: 2015; interview)

“The Literacy programme has really encouraged me, strengthened me at the time, it really empowered me...” (Richard: 2015; interview)

“The TL programme taught me about my body and how HIV works in the body...” (Rabecca: 2015; interview)

In summary, according to participants' learning in the TAC TL programme happened in two ways, informal and non-formal. The informal way of learning happened through raising awareness about HIV and AIDS, educating people about HIV and AIDS through reading, songs, emails, newspapers, videos, televisions, newsletters, leaflets, books, posters, wearing of the HIV t-shirt and actual debates. The TAC TL program had a system on how education and raising awareness about HIV and AIDS was done and different methods were used.

Secondly, the TL program also had a structured curriculum, with a manual serving as the primary instruction guide providing information on HIV and AIDS.

Thirdly, trainers and coordinators also assisted with the development of additional, easy-to-use reference material such as fact sheets in order to simplify the HIV and AIDS-related information, which was also translated into local languages (and facilitation also frequently informally simultaneously interpreted for participants) to overcome the literacy and linguistic challenges inherent in instructing such diversely representative groups of participants on quite complex HIV and AIDS-related issues.

What did participants learn?

The TL program was presented in such a way that people who could not read and write were also included and able to understand the science of HIV and AIDS, the health impacts and implications of antiretroviral treatment the pharmacological names of HIV and AIDS treatments and they could appreciate the importance of adhering to treatment. The TL programme encouraged people to adhere to and remain on treatment by concertedly working to help them understand all of the impacts and implications of treatment. Mofokeng notes:

“The Literacy program was good because some people could not read and write... [but they] were allowed to speak in Xhosa and could engage verbally with the facilitators”. (Mofokeng: 2015; interview)

Timothy felt his participation in the TL training raised his general understanding of a broad range of issues. He notes that participants received significant medical, technical and scientific information on HIV and AIDS, health and related issues, as well as learning relevant terminologies pertaining to the same. He

¹⁸Grabouw is a mid-sized town located in the Western Cape province of South Africa some 65 km south-east of Cape Town along the N2 highway. It is located over Sir Lowry's Pass from Somerset West in the vast Elgin Valley.

felt empowered by his understanding of HIV and AIDS, characterising it as comparable to the level of a doctor. What stood out for this participant was the simplified way in which difficult information was presented and packaged, communicated and shared as well as the participatory way in which the training was delivered.

“... the level of understanding of issues ... so-called doctors territory, it’s a medical field territory, and we could bring it home to ordinary people to understand, the ABC of how treatment works, the ABC of AIDS, the ABC of HIV, the ABC of what it is, how your body functions, how your body works, how your nervous system works, how your lungs work, how your kidneys work and how all of them are interrelated to one another and how by having treatment how that will impact and how that works within your body”. (Timothy 2015: interview)

Richard described how the TL program opened his eyes, his way of thinking and even presented many opportunities to so many things that he previously knew little or nothing about. Among other things, Richard said he learned:

“What are my rights, how to live and do the right thing... [t]o be open about who... you are. Treatment Literacy taught me about world governance. It opened my eyes and opened so many doors”. (Richard: 2015; interview)

Violet explained that she learned a great deal about high level politics from the TAC trainings and engagements – she said she felt like she was studying different modules; hence for her, TAC became a space for political activism which consistently inspired her. She admits that if it was not for TAC she would not have been as politically engaged and active as she is today. In Violet’s own words:

“For me ... [TAC] later became a space for political activism. It no longer only became a place where I could get help ...It was a space, post liberation, for young people like me to participate in politics”. (Violet: 2015; interview)

Rabbecca lived a very reckless life but after completing the TAC TL programme she changed her attitude and behaviour.

“...through the Treatment Literacy workshop, that's how I learned... I saw HIV in a different light, ...this was where my life started changing...” (Rabbecca: 2015; interview)

Going through the TL programme assisted Timothy to engage and use his influence in the community. What he learned made a strong and lasting impression on him.

“I will never ever forget the education...it is long lasting”. (Timothy: 2015; interview)

Mofokeng asserted that the TL training empowered participants, equipping them to engage with doctors about their medication since they better understood the treatment, its effect on the body, side effects and the science behind the treatment. As Mofokeng explained:

“Maybe once a doctor diagnoses you or gives you... treatment that is not for [your] illness you can dispute because you have an understanding”. (Mofokeng: 2015; interview)

TACs TL programme also addressed women's health and rights issues as well as governance issues pertaining to TAC and its structures. According to one of the participants, the organisation later incorporated even social security issues.

There was consensus among all of the participants that they learned a great deal through and as a result of attending the TAC TL program. The different participants drew more heavily on the information that resonated with them personally and were impacted differently by the learning process, which is not surprising given their diversity.

When asked what they had learned, participants referenced not only substantive HIV and AIDS information such as the appropriate way to take their medication, but they also pointed to the importance of reading to build on one's knowledge, and process-wise how to facilitate and participate in discussions and debates, among other things. Some participants said they also learned more about the political process and how to become confident lobbying the state to meet their needs. Others learned how to more assertively engage with health care workers, in particular in relation to their HIV treatment, which also helped them to inspire other community members. In sum, participants felt empowered by their information to respond to and address questions posed by community members on HIV and AIDS related issues that communities would pose at the time.

FACTORS WITHIN TAC WHICH ENABLE AWARENESS, UNDERSTANDING AND PRACTICE

This section explores participants' experience of TAC, in particular their accounts of being part of communities of practice after joining TAC. It also assesses whether or not this had any impact on participant's understanding of HIV and AIDS in the public healthcare context.

Participants' experience of TAC and their understanding of HIV and AIDS

In Timothy's view, the TL program made him appreciate the importance of collective leadership, and the sharing and exchange of ideas and views. As he recalled:

“What stands out [for me]... being part of TAC was the collectiveness and sharing ideas, exchanging views. It is still needed today, we must continue to develop our understanding and our lives because knowledge is power and without knowledge you can't speak truth to power”. (Timothy: 2015; interview)

Being part of TAC also opened avenues for participants to access job opportunities. As Nomvula's knowledge and confidence increased, she progressed through the professional ranks at TAC:

“I started as a volunteer in TAC until I became a Treatment Literacy Practitioner (TLP); I underwent a lot of training until becoming a national trainer for TAC”. (Nomvula: 2014; interview)

Violet, similarly, capitalised on her learning to rise through the organization

“I have three experiences of TAC. I have the first phase of my experience that I have been a volunteer, unpaid volunteer and that of being an administrative staff, and that of being a political staff” (Violet: 2015; interview)

Rabbecca also took note that through TAC a considerable number of members became paid HIV and AIDS Home Based Carers. She described her exposure to and experience in TAC as “life-changing”: once she understood how her behaviour was impacting on her health, she appreciated what she had to change and what she had to do to improve the quality of her health and life. .

Mofokeng remembers that his first activity when he joined TAC was to distribute such materials as pamphlets and brochures to educate and raise the awareness of communities, organizations and schools.

It is clear that TAC played a significant role in the lives of its members and staff: even people who had left the organization had predominantly positive memories of the organisation.

The impact of the organization was not restricted to the tenure of employment or association: as one participant explained, many former TAC members and employers moved on to leadership positions in other organizations, drawing on the skills, knowledge, networks and creativity acquired through their learning at TAC.

Another aspect of the TAC and TL programme emphasized by participants was its success at generating and increasing awareness among people, which consciousness-raising profoundly changed the lives of individuals, compelling them to take stock and become more critically engaged with social, political and economic issues and their implications for real lives, in particular the most vulnerable and marginalised members of society, including HIV and AIDS infected and affected people. The TL programme helped participants understand their rights, how to confront and formally challenge discrimination, and it increased their confidence to assert their rights in respect of both individuals and institutions. As Richard notes:

In the light of the above, it is clear that the TAC TL programme created and awareness within people, which changed their lives at an individual level, encouraging them to become more critically-engaged with real-life issues; it further bolstered their confidence so that they are afraid to disagree or to speak up for themselves, especially in relation to authority figures.

Another outcome of the TAC TL programme is that participants’ health awareness and knowledge increased as did their social consciousness. Therefore, although participants had divergent motivations for entering the organization, virtually all did so as volunteers, gradually gaining admission into programmatic, administrative or other formal position (in operations, management and other).

Participants remarked that TAC encouraged its members and staff to progress professionally. Only one of the participants was from the onset formally recruited into TAC through formal, organisational channels.

Moreover, it is clear that all TAC members and staff were expected to go through the TL programme. Study participants experienced the TL programme as empowering, informative, educational and as having equipped them to be HIV and AIDS treatment literate and the organisation's impact on communities and society more broadly. Moreover, all participants noted that ultimately everyone identified a place for themselves – which was not static but changed over time - within the organization.

Participants' community experience

This section explores participants' experience within communities (those from which they originated or those in which they resided) subsequent to being part of TAC.

Violet notes that TAC did not always have all the answers: that it, in fact, learned through trial and error how best to engage in community mobilization. She notes:

“It was a very interesting time for TAC... [the organization] was also learning how to organize in communities, so we were a trial and error group. People were exploring...what to do and what not to do so there was a lot of room to try out new things...” (Violet: 2015; interview)

According to Nomvula, once community members became aware that she was engaged in TAC treatment literacy and assisting people with appropriately taking their treatment, they became receptive to her, even to disclose their HIV status and to talk openly with her – to the extent that the community even began to proactively seek her help. With time, Nomvula began not only to engage in treatment literacy but also to organize and facilitate community dialogues and trainings. As she says in her own words:

“I ended up organizing community events, facilitating group discussions, people ended up coming [to me] for help. I facilitated family acceptance of [people's]...HIV status”. (Nomvula: 2014; interview)

Some of the challenges associated with working in communities were noted by Violet. She felt inundated by demands on her person and time once people became aware that she was working for TAC. She recounts feeling overwhelmed by community member's expectations, with needs far exceeding available resources, as attested by the fact that she received requests for assistance from as far as the Eastern Cape. Violet also felt that her work sometimes negatively affected her family and loved ones, with whom she frequently was unable to spend sufficient time as she notes:

“You become the counsellor, social worker of your community... The more successful TAC became the more people wanted, but that is also very overwhelming because we got our personal stuff that we are going through, you got your personal family responsibilities, it becomes too much”. (Violet: 2015; interview)

Richard and Timothy said in the beginning it was not easy introducing the topic of HIV and AIDS to the community. Some community members assumed that participants who wore a TAC HIV t-shirt were in fact infected with the disease. The t-shirt, which meant to provoke people's thoughts and prompt them to think about HIV and AIDS, instead elicited insults. Timothy:

"...people made remarks like, "jy het seker vigs man (he must have AIDS)", "het jy vigs? (Do you have AIDS)?" (Timothy: 2015; interview)

"...there was a lot of rumours and stories [in the community] ... 'jou AIDS gat kind' (AIDS body), 'what is he still doing around, he is going to infect our children too'. (Richard: 2015; interview)

Timothy also remembers starting a TAC branch in his house, and the struggles he encountered recruiting members of the community because of stigma and discrimination around HIV and AIDS.

One of the participants, Rebecca, had more positive recollections of this time:

"...I wanted to be active in the community, I wanted people to know, what I learnt from the t-shirt that I wear...people would come up to you because it says HIV on it and people would come to you and ask if you are HIV positive... now you have an answer that person because the t-shirt creates awareness... so that people can know that there is an organization like TAC..." (Rebecca: 2015; interview)

"It makes you powerful, especially when they mistreated my daughter at the hospital and I had a TAC t-shirt on. They called me and when the doctor saw me he said he knew me [he didn't know me personally]...but because of the t-shirt..." (Rebecca: 2015; interview)

From the above it is evident that for the most part study participant's experiences of the TL programme were positive, since it afforded them the opportunity to raise awareness within their communities about HIV and AIDS, treatment options, available support, and so forth; however, this was not without a toll on the participants, many of whom were at times overwhelmed by the demands on them and the impact of their work on their families and lives.

Participants emphasized the many positive aspects of their work: they recognised that engaging with communities strengthened their confidence and was personally rewarding – they especially appreciated being able to "give back" to their communities by educating and raising their awareness on HIV and AIDS-related issues. Through the TL programme participants were empowered to engage the community on the harm caused by discrimination against people living with HIV and AIDS.

BARRIERS TO AWARENESS, UNDERSTANDING OF TAC TL PROGRAMME

This section outlines barriers to awareness and understanding in relation to TAC TL programme.

Violet noted the difficulty of translating into local languages the scientific HIV and AIDS terminology. This was why TAC had to be creative in representing certain issues through song, role-play and drama.

Mofokeng also identified language as a barrier: he noted that at times TL presentation templates and material were available in English, while the facilitation was in Xhosa. Mofokeng noted that it was also challenging referencing or drawing on policy documents such as the National Strategic Plan on HIV and AIDS (NSP), which are overwhelmingly written in English, which tends to be very technical and legalistic.

In Richard and Timothy's view similarly, language was and remains one of the most significant barriers to awareness and understanding of the content of TAC's TL programme. As Timothy describes:

"I think the...difficulty for me... [with] the Treatment Literacy programme and being... [In [TAC] is still the language barrier. It is a fact that you come to the TAC event [which is] overwhelmingly African and rightfully so, but you don't understand because the language is [Xhosa instead]...of English and you have to raise your voice to a point of order. 'Ek wil my taal praat kan jy vir my translate'.¹⁹ (Timothy: 2015; interview)

"...you would always wave your hand when you are in class or clap your fingers but sometimes you know they just carry on and then somebody else from the class say sorry, sorry, sorry guys we need to translate". (Richard: 2015; interview)

Rates of remuneration were identified by Nomvula as an indirect barrier: because TL trainers were relatively poorly paid for the hours they worked and the amount of time and effort they put into the training, there was a level of disgruntlement among some of them which negatively affected their productivity and demeanour. Nomvula similarly flagged the number of people who had to be trained as another barrier, since it meant that trainers were unable to provide every participant with one-on-one attention; another indirect result was fatigue of trainers.

Some participants noted that TL trainers' travel and commuting times, especially between workshops and trainings was another factor contributing to their fatigue. Nomvula noted that it often felt as if they were on the road all the time. She also highlighted the administrative demands on TL trainers as another drain on their energy since there were so many forms that had to be filled in. In Nomvula's own words:

"(Laughing) at the time there was a lot of travelling. I used to be very tired all the time. Collecting of data, the paper work was so tiring. I feel that that was not my field, I don't know, I don't want to insult people who created those forms, but that was a lot to do". (Nomvula: 2015; interview)

One participant felt that the training provided excessive information overwhelming not only trainers but also participants and potentially undermining their ability to effectively engage with and understand the material.

Another participant explained that even though the training placed heavy emphasis on activism and HIV and AIDS, denialism of the South African government and their prioritization of other development imperatives made advocacy – especially in the early 2000s – particularly challenging. The TAC TL

¹⁹If translated from Afrikaans to English it means: "I want to talk my language, please can you translate for me."

programme enlightened and empowered people at the time and they were also recruited as members to join the struggle for 'access to treatment'. A lot of global and HIV politics were included to open people's minds to their realities.

One of the down sides of the TL programme, according to one of the participants was that the trainings were not accredited, which was not initially regarded as a problem but became an issue when participants wanted to pursue job opportunities outside of TAC – they believe they were not taken seriously because the knowledge they acquired through TAC's TL trainings was not accredited.

Most of the participants felt that language was a barrier to their fully understanding and being able to impart the content of the TL programme to other people. The fact that all the HIV and AIDS-related material was published in English with limited or no translations in local languages was a serious challenge in this regard. A related challenge was the need for trainers to engage in informal translation – and simplification – of the English material, often as they were facilitating trainings. Some participants contended that this resulted in the information becoming diluted at times. To get around language constraints, trainers resorted to creative approaches – for example song, drama, poetry and role-playing – to more accurately convey information.

Did TAC and its TL programme inspire people and participants?

The aim of this section is to look at the impact that the TAC TL program had on participants.

Nomvula and Richard feel TAC played a significant and positive part in the lives of many. For her and his part:

“TAC did a good job; they are still doing a good job...” (Nomvula: 2014; interview)

“I must say viva TAC you have taught me very well, you educated me very well, you have sent me to places that I never ever would have thought of going [overseas]...” (Richard: 2015; interview)

Violet felt that the work they did in TAC and in the TL programme gave them a sense of being part of something bigger and that they were doing something towards fighting for access to treatment at a time when access to treatment was not available for the poor. She also felt that helping other people infected or affected by HIV and AIDS helped them deal better with their own situation. As Violet notes:

“I think it took many of us out of depression because by learning and using the information to help others allowed us to not only have self-pity and see ourselves as victims but also see ourselves as agents of change as advocacy activists”. (Violet: 2015; interview)

Richard says that despite no longer being active in TAC people still reach out to him to assist people who are in denial about their HIV status.

“I spoke to a friend of mine and she says to me I would like you to speak to my sister’s son, he stays in this area and he is twenty five and he has got full blown AIDS, is doing drugs and I would like you to come and talk to him”. (Richard: 2015; interview)

Violet remembers the sense of ownership, a sense that the organization was yours because you were giving back to the organization. She remembers how they instilled accountability amongst themselves first so that they can then hold TAC leaders to account but most of all she remembers the information sessions, workshops and the education that was done in the branches to make sure that branches understand and have the knowledge about HIV and AIDS, in the branches.

We used to finance ourselves to go to the provincial executive committee (PECs) meetings, no one gave us money. We were then given money from the meeting to come back, we then gave that money to our members and from that build our level of ownership, that the organization is yours. (Violet: 2015; interview)

One of the events that really stood out for Timothy and something he says he will never forget was when one of his best friends disclosed their HIV status in the church and he felt that that laid the foundation for the work that TAC was doing in that area.

The single most biggest event in my personal life is when one of my friends could speak openly at a church event about his HIV. He laid the foundation for me, he put us on the map, his openness, his willingness to speak about his own illness, and he was my leader. (Timothy: 2015; interview)

The above findings indicate that participants that went through the TAC TL program felt empowered, they became more confident to speak out and some were inspired. There was a lot of organizational development, staff capacitating, information-sharing and knowledge building within TAC at this time that made people feel they were part of something bigger. Fighting for access to treatment and helping people infected and affected by HIV and AIDS, helped TAC members and staff cope and deal with their own challenges, including HIV and AIDS-related ones. Some of the participants are no longer very active in TAC, however, their association and work with TAC is still well-known within communities, as attested by the fact that they are still frequently sought out and consulted to advice on HIV and AIDS-related matters. This section shows that the reach and impact of TAC’s work is still tangible and resonant for both former associates of the organisation and the broader community – the earlier noted challenges notwithstanding.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

“The [treatment literacy] programme did make an impact on my life because I know how HIV multiplies in my body and how I can prevent HIV by using a condom”. (Mofokeng: 2015; interview)

INTRODUCTION

Chapter 5 explain and examines the key themes in the findings presented in Chapter 4, after which it sets out the study conclusions and recommendations, highlighting the significance and relevance of the research. As indicated in the literature review, this study explored participant’s awareness and understanding of their experience in the Treatment Action Campaigns Treatment Literacy programme.

OVERVIEW OF FINDINGS: LEVELS OF AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH

An outline of the findings presented in Chapter 4 led to the interpretation that the men and women’s levels of consciousness, understanding and practice of HIV and AIDS, health and rights differed but individuals were generally keen to step into spaces and places after the TAC TL training. Grassroots mobilization was a key success of TAC. This was completed through AIDS awareness and treatment literacy campaigns in schools, factories, community centres, churches, shebeens and through door to door visits in the African townships. By far the majority of TAC volunteers were poor, unemployed African women, many of them HIV positive mothers desperate to gain access to life-saving drugs for themselves and their children (Robins: 2004) and (TAC Equal treatment magazine, Issue 22/May 2007)

The findings illustrate that the men and women’s social and economic circumstances, background and how they experience the learning context, had an impact on participants as learners. This can advance our understanding of how to improve awareness, understanding and practice of HIV and AIDS, health and rights. For example, when we look at the findings in Chapter 4, the participants honed in on the process of learning as opposed to the substantive content of what was learned. A primary finding of the study is, therefore, that how an individual perceives the world is central to their learning process. Learning is thus a substantially personal experience; however, the development of the individual frequently occurs within a group dynamic, which is supported by Freire and Mezirow as discussed in Chapter 2.

DISCUSSION OF THE FINDINGS

In my introductory chapter I outlined how the racial discrimination experienced by all black South Africans during the apartheid regime - from 1948 to 1994 – profoundly impacted black people’s health adversely. This study drew on theorists which explore learning in social movements and adult education

that have direct relevance to the research in terms of the site of practice and conceptions of learning and teaching bearing on the findings provided in the next sections: participants' histories, life experiences and socio-economic context; participants' motivation for becoming part of TAC; their perceptions of TACs TL programme; how participants' learnt; what participants' learnt and what participants' learning meant for them.

This study explored the experience of six people who participated in a Treatment Literacy programme implemented by the Treatment Action Campaign in the Western Cape in the period 2001 to 2009. The study examined participants' awareness and understanding of their (learning) experience within TACs TL programme and addressed: What attracted participants to TAC; how and what they learned; their perception of the learning process; and whether it had any bearing on their perception of the TL programme.

Participants Histories, Life Experiences and Socio-Economic Contexts

The findings shows that all six study participants were from lower income communities in the Western Cape at the time that they joined TAC. Their profiles and life experiences illuminate the differences and similarities between them: among other things, they are diverse in age, race, gender and levels of poverty and life experience. Although all of the participants are currently living in brick houses, this was not the case for many of them during childhood.

The findings, moreover, confirm that TAC's education and community mobilization reached people from all walks of life: those infected with HIV and AIDS as well as those affected by the disease. One of the ways through which this was accomplished was, as Heywood (2009) confirms, campaigns that were from the outset clear, easily understandable, emotive, and thereby life-saving, amplifying stories of the human cost of denial of HIV medication to a national and international audience. Robins (2004) claims that one of TAC's key successes has been its grassroots mobilisation across racial and class divisions, representing "globalisation from below". It is this spirit of the mass movement that encouraged TAC to establish a wide-spread HIV and AIDS education campaign with many people who never had formal schooling.

Participants motivation for becoming part of TAC

The study found that most (4) of the participants in this study joined TAC at a time when access to treatment was not available in South Africa. Between 2001 and 2002, most of the participants were actively involved in the TAC campaigns and activities at a very difficult period in the HIV and AIDS history of the country. This suggests that TAC was, at the time, an organization capable of providing the kind of support participants were looking for.

The above confirms what Mezirow (1991) alludes to, namely that social interaction transforms participants from frightened, stigmatized individuals to empowered, confident people. By talking with others, people realized they were not alone and that as a group they could change society.

Participants perception of TACs TL programme

Most of the participants entered TAC without a background in health and neither were they, with the exception of one male participant, involved in any form of politics.

The participants had no conception of the volume of information, the range of HIV and AIDS-related topics and issues they would be exposed to and the impact – positive or negative – that this would have on their lives. While some participants reported that they were inspired, others felt empowered, and others felt the TL programme boosted their confidence and raised their level of awareness and understanding, but also for some, feeling of being overwhelmed.

Freire (1985) holds that the issue of literacy and power does not begin and end with the process of learning how to read and write. Instead, it begins with the understanding that one's existence is part of a historically constructed relationship of power, marginalized socially, economically and politically.

How participants learned

The study found that learning in the TAC TL programme happened through both informal and non-formal learning. Education played a key role in building the capacity of participants through training sessions, awareness-raising discussions and debates on issues relevant to the aims and objectives of the TAC TL programme. The findings show that TAC used a variety of methods and ways to communicate HIV and AIDS to the people.

Informal learning

The study found that reading was the medium used for most of the informal learning in TAC, which sought to raise awareness and educate people about HIV and AIDS. Any form of reading, whether individually or within branches, was strongly and consistently promoted. However, songs were used where participants struggled to commit the information to memory or could not properly pronounce the terminology used or could not read or write. Video was another medium used either in the trainings and workshops or for distribution in TAC branches and communities. Other TAC learning materials included newsletters, books, leaflets, posters and publications. The wearing of the TAC HIV positive t-shirt was also part of raising awareness and educating people about HIV and AIDS with a special emphasis on breaking the stigma of HIV and AIDS in the communities. Learning also happened through participating in and organising marches and protest action and community meetings.

Mezirow (1991) alludes to social interaction that transform participants from frightened, stigmatized individuals to empowered, confident people. One of the participants when interviewed explained how the TL training helped her not to focus on herself and that it took many of them out of depression because the learning and using of information to help others assisted them to see themselves as agents of change.

Non formal learning

The study found that the TAC TL programme had in place a system for HIV and AIDS education and raising awareness about HIV and AIDS was done. The learning in the TAC TL program was structured and systematic. The programme came with a curriculum and a manual that informed the way how information and knowledge about HIV and AIDS was specified and constructed. The programme had an HR component which consisted of peer educators, practitioners, trainers and coordinators from district level to national level. When TAC staff (trainers and coordinators) had to be trained, different professionals with different expertise were called in to run the TL trainings. People from other countries and organisations that are working in the same field as TAC were called in to assist with the TL trainings. During these trainings all topics were broken down into detail with practical examples and intense discussions. Materials went hand in hand with the trainings, reading was always promoted and assignments and group work were all part of the TL trainings. These training then had to be duplicated in provinces, districts and branches.

One of the participants explained that the TL manual had so much information that the trainers had to develop fact sheets in order to simplify and break down the information. Another reason why the fact sheets were developed was to make information user friendly but also accessible. The material had to be translated into the local languages because all the literature and material about HIV and AIDS only came in English at the time. Treatment literacy became part of and was TAC's culture.

The views of Lave and Wenger (1991) are relevant to this research because they foreground learning in terms of participation within a group which they term 'a Community of Practice'. Learning is not viewed as the primary purpose of the group; learning is embedded in the context and practices of the group. TAC's TL programme was the shared interest of those affected and infected with HIV and AIDS, seeking information and life saving ARV treatment. The group engaged people in shared activities and shared information with each other. They learned from each other and they learned together. The group developed and shared their stories, similar to the way learning happens within the TAC TL programme.

What participants learned

The goals of the TL programme was to empower individuals and communities to take control of their health through understanding of HIV and AIDS prevention, treatment, and care, understanding the rights and responsibilities of patients, and the related social issues. PTL was primarily intended for individuals who visit public health facilities and other places where communities gather within TAC districts. Secondly, the PTL programme provides HIV and AIDS education and training to TAC members, support groups, and other NGOs who in turn will educate the community-at-large (TAC: 2008).

The TAC curriculum indicates that the content of the TAC TL programme had to be engaged with very strictly by both facilitators and those participating in the TL programme due to the nature and seriousness of the information that could save the lives of people living with HIV and AIDS when they go back to their respective communities. Some of the participants when interviewed did indicate that they felt overwhelmed with the information overload during the TL sessions but the discomfort they felt was in a good way.

The findings tell us that participants learnt about HIV and AIDS terminologies and scientific information, HIV prevention, what is my rights, the body (Human Anatomy), HIV treatment, how to live healthy and do the right thing as a person living with HIV, to be open about whom you are, world governance, political activism, women's health and women's rights and the governance of TAC and its structures, to mention a few.

What participants' learning meant for them

When participants answered the question about what they learnt, they explained more about what their learning meant for them.

The findings indicate that while all participants' went through the same training the impact of the training on participants differed from individual to individual. This could be due to the fact that people did not join TAC for the same reasons. Some needed access to information, others wanted access to treatment and participants' were recruited by the leadership of TAC, literacy practitioners of TAC and TAC members. Participants learnt to be comfortable with themselves and who they are. Some participants felt empowered and inspired after the trainings. Mezirow (1991; 1994) argues that the way an individual sees the world is central to the learning process, with learning being a personal experience, which entails development of the individual. TAC TL programme falls within the radical tradition of adult education.

FACTORS WITHIN TAC WHICH ENABLE AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS WITH A PUBLIC HEALTHCARE CONTEXT

This section explores participants' experience of TAC and their experience of being part of communities after joining TAC and whether it changed (or not) their understanding of HIV and AIDS in the public healthcare context.

Participants' experience of TAC and how it changed (OR NOT) their understanding of HIV and AIDS

Study participants experienced the TL programme as empowering, informative, educational and as having equipped them to be HIV and AIDS treatment literate, to understand the organizational structure, programming, environmental dynamics within which TAC operated and the organisation's impact on communities and society more broadly. Participants' health awareness and knowledge increased as did their social consciousness. Moreover, all participants noted that ultimately everyone identified a place for themselves – which was not static but changed over time - within the organization. The findings tell us that the TL programme created an awareness within participants that changed their lives at a personal level on being critical about life. I agree with Newman (1995) on his views that it may be argued that the most powerful learning that takes place in social movements is incidental learning which occurs during action, and it may only be in hindsight that we recognise that learning has taken place. For example, people in community organizations and community development projects learn to write submissions, run an office, canvass community opinion, and lobby public servants in the course of conducting their community activities.

Community experience on health rights

Most study participants' experiences of the TL programme were positive, since it afforded them the opportunity to raise awareness within their communities about HIV and AIDS, treatment options, available support, and so forth; however, most of their family lives and personal lives suffered as a result of TAC involvement, although no-one regret this. The findings further tells us that once the communities became aware that they were health activists with TAC, people would come and seek help on a range of health related issues but mostly HIV and AIDS. Some of the participants felt overwhelmed at times and they were surprised that community members would so easily confide in them about their HIV statuses but people were desperate and needed information that could save their lives. Participants' engagement with and in their own communities was good for their confidence and it felt very rewarding to give back to communities in the form of education and raising awareness. Through the TL programme some participants felt that they were empowered enough to engage with the community against discrimination of people living with HIV and AIDS and the HIV t-shirt was one of the methods used by TAC to break

the stigma through wearing the HIV positive t-shirt; but it was not easy, especially when the communities' first response was always that of thinking that those that wear such a t-shirt is HIV positive.

Traditionally, both informal and non-formal education has played a major role in building the capacity of social movements through inter alia: training sessions, awareness-raising discussions and debates on issues relevant to the aims and objectives of the social movement concerned (Newman: 1995). This kind of learning which is affirmed in social movements, like TAC, is learning which leads to knowledge which enables people "to act on their learning as a group" and as "individuals". The Treatment Action Campaign (TAC) affirms this way and kind of learning.

BARRIERS TO AWARENESS AND UNDERSTANDING OF TAC TL PROGRAMME

The findings inform us that most of the participants felt that language was a barrier in some way, form or the other. One of the core reasons given was the fact that all the material on HIV and AIDS was published in English without translations in local languages and that it became difficult at first to understand the content thereof. Secondly as a lay person you needed to translate the information into local languages and thirdly you also needed to simplify the information, it was a bit too much but it had to be done at the time. In a way this almost diluted some of the information at times. That is why people had to be creative during the trainings with songs, drama, poems and role play to get the message across when language became a barrier. Then there was the administration side of the programme which some felt was a barrier in terms of the paper work with so many forms that had to be filled in, the travelling was a challenge as they were on the road all the time and they were not paid enough money.

Did TAC and its TL programme inspire people and participants?

The findings tell us that TAC left a long lasting mark on each and every individual that was part of the organization whether it was for a short time period or longer. There was a lot of organization building; knowledge building and sharing of information that was going on within TAC that made people feel they were part of something bigger. People felt that being part of TAC and fighting for access to treatment and helping other people affected and infected with HIV and AIDS, helped them in turn to deal with their own challenges of being affected and infected with HIV and AIDS. Some of the participants are not active in TAC anymore but up until today, people still ask them to come and assist people living with HIV and AIDS.

Adult learning is associated with many concepts but for the purposes of this study I drew on Mezirow (1991; 1994) who suggests all learning is based on experience. Learning can be viewed as a process of altering, modifying or transforming an individual's attitudes, beliefs, perceptions and practices with knowledge being created through critical dialogue and reflection, triggering the transformation of

experience which then becomes learning (Mezirow: 1994). Paulo Freire (1985; 72) further argues that learning is aimed at understanding oppression with the view to changing society for a better quality of life.

CONCLUSION

My research question explored the experiences of six people who participated in a Treatment Literacy programme implemented by the Treatment Action Campaign in the Western Cape in the period 2001 to 2009. The study examined participants' awareness and understanding of their (learning) experience within TAC's TL programme and addressed: What attracted participants to TAC; how and what they learned; their perception of the learning process; and whether it had any bearing on their perception of the TL programme. My theoretical framework drew on the field of adult education and theories and theorists which have direct relevance to this study in terms of the site of practice (social movement) and its conceptions of learning and teaching (informal and non-formal). These aspects enabled me to identify with and analyse participant learning.

This research focused on the learning methods, tools and strategies used in the TAC's TL programme in order to assess what elements remain relevant for organisations conducting adult education and work in communities today. The study further examined and documented important educational and learning practices from which to draw inspiration for future HIV and AIDS initiatives in the interest of building a critically informed and active citizenry.

Many organizations working in South African communities seek innovative ways to transfer knowledge, inform, transform and mobilise communities around a range of issues, including health and social. South Africa has made significant strides and now has the political and social will necessary to address the HIV and AIDS and related challenges that once seemed insurmountable. It is hoped that this study will make a positive contribution to the existing literature on adult education as well as provide civil society with new and valuable ideas to enhance their engagement with communities.

Thus this study:

- Identified that while some participants reported that they were inspired, others felt empowered, and others felt the TL programme boosted their confidence and raised their level of awareness and understanding. HIV education has given people with HIV dignity and knowledge to take control of their lives.
- Found that learning in the TAC TL programme happened through informal and non-formal learning.
 - Informal learning happens through reading, song was used where participants struggled or could not read or write. Video was another medium used either in the trainings and

workshops or for distribution in TAC branches and communities. Other TAC learning materials including newsletters, books, leaflets, posters and publications. The wearing of the TAC HIV positive t-shirt was also part of raising awareness and educating people about HIV and AIDS with a special emphasis on breaking the stigma of HIV and AIDS in the communities.

- Non-formal learning – The TAC TL programme was structured and systematic and learning is embedded in the context and practices of the TL programme and took into account the context of the participants.
- Illustrates that TAC’s education and community mobilisation strategy to reach people were from the outset clear, easily understandable, emotive, and thereby life-saving.
- Found that learning in the TAC TL programme was a personal experience for participants and that the TAC TL programme was used as a tool to empower people.
- Tells us that most of the participants felt that language was a barrier in some form or the other. That is why people had to be creative during the trainings with songs, drama, poems and role play to get the message across when language became a barrier.
- Succeeded in telling us that TAC left a long lasting mark on each and every individual that was part of the organisation, whether it was for a short time period or longer. People felt that being part of TAC and fighting for access to treatment and helping other people affected and infected with HIV and AIDS, helped them in turn to deal with their own challenges of being affected and infected with HIV and AIDS.

The South African National Strategic Plan on HIV, TB and STIs 2017 – 2022 policy document serves as a roadmap towards a future where HIV, TB and STIs are no longer public health problems. Ending HIV and AIDS require a sustained focus on health promotion by creating conditions that allows individuals and communities to make informed choices regarding HIV prevention, care and treatment - and empowering of communities and individuals to act on those choices. A strong focus must be on the prevention of HIV infection among adolescent girls and young women because of the high rate of infection in this section of the population (NSP on HIV, TB and STIs 2017-22). The ability from the Department of Education to incorporate proper HIV and sexual education as part of the school curriculum for the different phases and stages of a students’ life is very important, using a combination of interventions that deliver high impact.

The study concludes that the TAC TL programme has inspired, empowered and boosted participants’ confidence and at the same time raised their level of awareness and understanding. The HIV education has further given people with HIV dignity and knowledge to take control of their lives. Participants also felt that being part of TAC and fighting for access to treatment and helping other people affected and

infected with HIV and AIDS, helped them in turn to deal with their own challenges of being affected and infected with HIV and AIDS. A primary finding of the study is, therefore, how an individual perceives the world is central to their learning process. Learning is thus a substantially personal experience; however, the development of the individual frequently occurs within a group dynamic.

RECOMMENDATIONS FOR FUTURE RESEARCH

The scope of the research was limited to the experience of six men and women who completed the TAC TL programme therefore I would recommend and encourages further research to explore the questions below:

- What other divides exist between awareness, understanding and practice? Methods, other than information-dissemination, by which to raise awareness, provoke thought and understanding of personal practice in order to catalyse attitudinal and behavioural change, with special emphasis on the youth cohort.
- What lessons and best practice exists to improve access to? The socio-economic vulnerability of certain social groups, especially HIV-positive women and other, and the factors impeding their enjoyment of health rights in South Africa.

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APPENDIX 1
UNIVERSITY OF CAPE TOWN
RESEARCH PROPOSAL FOR MASTERS DISSERTATION
EDN6015F

Interview Schedule

This proposed study is an exploratory qualitative research study. The qualitative research methods seek to investigate human behaviours and the social world that people live in. The study will explore the participants awareness and understanding of their experience in the Treatment Action Campaign, a social movements literacy programme, what attracted them to TAC, how they learnt, what they learnt, how the experience changed (or not) their understanding of HIV/AIDS, sexuality, taking treatment and other health related practices.

I will look for the following indicators in the interview

PARTICIPANT PROFILES

1. Demographic questions

2. How/where did they learn (informal/non-formal)

TAC PROGRAMME

3. What they learnt (Level of understanding on HIV/AIDS, Do they unlearn dominant understandings of things/ prejudices)
 - a. What is emphasised? That they learn the procedures of taking their medicines or that plus add bigger questions
4. Are there sufficient opportunities for learning

OUTCOMES

5. What did they value (relevance of the content to the learner)
 - a. Are learners given space/ chance to talk/ bring up issues/ change the topic?
 - b. Do they become more conscious of their own situations, seek solutions, 'become agents of change'

6. Do learners have the ability after the programme to develop some political understanding of their situation?

7. Or active citizens

APPENDIX 2
UNIVERSITY OF CAPE TOWN
RESEARCH PROPOSAL FOR MASTERS DISSERTATION
EDN6015F

Interview guide

Interviews questions

I will introduce myself, explain the research project again, purpose of the interview, expectations, what will happen with the results, what their consent means, confidentiality and permission to record the interviews.

1. **Participant's profiles (life experience and back ground questions)**
 - a. Born, age, language, learning back ground, involvement in health programmes, employment status, shelter, activism
 - b. What were they involved with before Treatment Action Campaign (TAC)

2. **TAC programme (Level of understanding)**
 - a. Their motivation for becoming part of TAC, why others left TAC?
 - b. Their interpretation of TACs Treatment Literacy Programme (TL)
 - c. Their experiences of TAC
 - d. Their participation in TAC
 - e. Did they learn something?
 - f. What they learnt
 - g. Barriers to awareness and understanding
 - h. The materials, the facilitator – how did they interact,
 - i. What led them to become active in the community, did it have an impact on their relationships at home at work in the wider community etc.?
 - j. How they feel about their rights
 - k. Their views on the state's role in promoting health rights

Appendix 3
UNIVERSITY OF CAPE TOWN
RESEARCH PROPOSAL FOR MASTERS DISSERTATION
EDN6015F

CONSENT FORM

This is an exploratory qualitative research study that seeks to investigate human behaviours and the social world that people live in.

Thank you for agreeing to participate in this study. My name is Fredalene Booysen and I am a Masters student from the School of Education at the University of Cape Town.

Explanation of the research

The study will explore the participants awareness and understanding of their experience in the Treatment Action Campaign, a social movements literacy programme, what attracted them to TAC, how they learnt, what they learnt, how their experience changed (or not) their understanding of HIV/AIDS, sexuality, taking treatment and other health related practices.

The first aim of the research is to retrieve important educational and learning practices and draw inspiration for future initiatives in the interest of building a critically informed and active citizenry. Secondly, the study will contribute to knowledge with regard to how behaviours are changed and in addition it will contribute to a growing body of literature on learning in social movements which includes risk taking behaviour. Lastly, my personal interest in documenting these stories is an attempt to encourage and inspire those that are infected and affected by the disease and to help them to manage their circumstances more effectively.

What will happen in this study?

We will conduct an interview with you and the interview will explore aspects of your experience of the Treatment Action Campaign's (TAC) Treatment Literacy (TL) programme and your opinions and views about how the programme influenced you. It will take between an hour and an hour and a half of your time. We would like to record the interview on a tape.

What will happen with the information?

All the information I collect will be confidential. No-one besides you and us will have access to the transcribed tapes. The final report will anonymise (not disclose your names and give you false names) reporting such that it will not be possible to identify an individual in the report. The report will be used to provide a description of the organisation literacy programme, what and how participant's learnt, what they learnt, how their experience changed (or not) their understanding of HIV/AIDS, sexuality, taking treatment and other health related practices.

Voluntary

Your participation is entirely voluntary. There will be no adverse consequences if you decide you do not want to participate.

Benefits and harms

The interview will collect information about your views, experiences and opinions. It should not cause you any distress or harm. If at any time you wish to stop the interview because of discomfort, you are free to do so. The benefits to you are that you have an opportunity to talk and reflect on your experience. I will benefit as it will be part of my Masters' qualification and the research will be published.

If you have any further questions? You can contact Dr Salma Ismail at the School of Education on 021- 650-3253 or Salma.Ismail@uct.ac.za if you have any further questions about the study.

If you are willing to participate, can you please indicate below that you have understood what the study about and that you are willing to participate in the study?

Vuyiseka
Name

H. Dubule
Signature

13.3.15
Dated