



## A COMPARATIVE ASSESSMENT OF ANTIRETROVIRAL THERAPY PATIENTS' SUPPORT GROUPS IN MANGWE AND NKULUMANE DISTRICTS OF ZIMBABWE

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**ABSTRACT:** *The article assesses the role Support Groups (SGs) for patients on Antiretroviral Therapy (ART) in Mangwe and Nkulumane districts of Zimbabwe. Data collection was qualitative in nature through the inductive means of interviews, focus group discussion and questionnaires. Stratified random sampling was used. St. Anne's Brunapeg Hospital and Plumtree District Hospital (for Mangwe) were each classed as strata. Only one clinic offers ART services in Nkulumane and this served as a strata. Fourteen SGs were interviewed as focus group discussions and one hundred and six as questionnaires. The empirical findings reveal that SGs are of critical value in the ART programme. They provide inter alia emotional support, peer counselling, information on ARVs, access to financial support and training. The SGs are vital in the ART programme and are in dire need of funding.*

**KEYWORDS:** ARVs, PLHA, SGs, ART, Mangwe, Nkulumane.



## INTRODUCTION

Mangwe district (Mangwe) is located in Matabeleland South Province in the southern part of Zimbabwe. This rural district is characterised by low rainfall patterns and persistent droughts. Its proximity to South Africa and Botswana has led to a huge number of emigrants. The district is serviced by two hospitals, Plumtree District Hospital (State Owned) and St Anne's Brunapag Hospital (Catholic Mission owned). These two hospitals have Opportunistic Infection Clinics (OI) and are involved in the implementation of the Anti-retroviral Therapy (ART) programme and the outreach services. The District is in the ecological regions 4 and 5 and on average receives between 450-500 mm of rainfall and in the 2011-12 rainfall seasons, the District received an average of 365,4mm of rainfall (Mangwe Agritex, 2018). Temperatures are as high as 40°C during summer months and on average 13°C during winter (Practical Action, n.d.). These climatic conditions make the area very vulnerable to meteorological hazards such as droughts, floods and gusty winds, as well as lightning and epidemics during the wet and hot season (Practical Action, n.d.). The population is estimated at 88 000 people with more than 77 000 cattle. Vegetation is patchy and this renders the area very vulnerable to environmental hazards such as flooding, soil erosion, gusty winds and general environmental deterioration (Practical Action, n.d.)

Nkulumane district (Nkulumane) is located in Bulawayo Metropolitan Province. Bulawayo is the second largest city in Zimbabwe with an estimated population of 1.2 million in 2020. Bulawayo covers an area of about 1,707 square kilometres (659 square miles) in the western part of Zimbabwe. The population in Bulawayo Province was relatively young with 34 percent aged below 15 years and slightly above 3 percent for 65 years and above (ZimStat, 2013). Bulawayo's last population census was in 2012. According to the census, activity and labour force constituted 66 percent of the total population. Out of these, around 60 percent were in the labour force. The proportion of those in the labour force who were unemployed was about 28 percent. Almost 1 percent of children ages 10-14 years were economically active. The proportions of those not in the labour force who were students was 39 percent, homemakers 42 percent, and retired/sick/too old 14 percent. Out of those who were employed, the highest proportions (32 percent) were engaged in services related occupations, followed by Business and Finance (8 percent) (ZimStat, 2013).

Only one clinic offers ART services in Nkulumane. Nkulumane, which is urban has access to two major hospitals in Bulawayo, namely Mpilo and United Bulawayo Central Hospitals (both State Owned). Mpilo Hospital has a fully equipped Opportunistic Infection (OI) clinic with diagnostic machinery and counselling services. It is also serviced by some Non-Governmental Organisations (NGOs) involved in HIV and AIDS services. These include Population Services International (PSI) NewLife Centre and Matabeleland AIDS Council (New Start Centre). These centres give support to People living with HIV (PLHA) and their SGs.

Zimbabwe National Network for People Living Positively (ZNPP+) (2011) defines SGs as a group of people who share the same problem, meet regularly, and provide each other with various types of nonprofessional-non material help. The help may take the form of providing relevant information relating to personal experiences, listening to others' experiences, providing sympathetic understanding and establishing social networks. The ZNNP+ was founded in 1992 and officially registered as a Non-Governmental Organisation (NGO) in 1999. The organisation became the national umbrella body representing and coordinating interests and activities of SGs and organisations of PLHA throughout Zimbabwe. The ZNNP+ seeks to



emancipate PLHA through skills development, counselling, education and rights lobbying. The goal of ZNNP+ is to ensure that those infected and affected by HIV and AIDS have access to holistic care and support, prevention, treatment and mitigation in a transparent and accountable manner.

The current ZNNP+ membership is estimated to be +3000 SGs. The network has a governance structure is made up of the National and Provincial Executive Committees and the Secretariat. Membership is through SGs, which consists of 10-15 members. The SGs pays an annual membership fee and through their affiliation become part of the national network of PLHA. The SGs are mostly managed by group members themselves, often with support from service providers or professionals who may be given the role of facilitating discussions and link the members with service providers. It is an intricate network.

Oxfam (Zimbabwe) works in hand in hand families affected by HIV and AIDS, providing support and access to healthcare. This involves health education to encourage good hygiene practices and help with accessing appropriate medications. Oxfam also engages communities in strengthening their abilities to care for PLHA (Zimbabwe/Oxfam GB, 2014). Anti-retroviral drugs (ARVs) are drugs used in the clinical management of chronic HIV disease and AIDS. ARVs have significantly increased survival rates and reduced mortality rates. ARVs improve the quality of life and reduce incidence of HIV related OIs. The ART programme in Zimbabwe aims to improve the quality of life of PLHA and access to healthcare.

The barriers to ART adherence include *inter alia* lack of social support, income, adequate shelter and food (Simoni *et al.*, 2002). Poverty in itself is likely to affect adherence, as financial resources may need to be directed elsewhere, funds for travel to the ART clinic may not be available, and child-care may not be readily accessible for parents who attend clinic visits. The competing demands of several responsibilities such as work and family life, along with the stresses associated with poverty and difficult life circumstances such as unemployment, may obviate an acknowledgement of the importance of complying with treatment regimens in general (*ibid*). The psychosocial barriers to adherence that may potentially be faced by patients receiving ARVs include, health illiteracy, perceived social support, mental health, substance abuse, and stigma (Kagee, 2004).

ART is essential in mitigating the devastating impact of the epidemic (Medicins Sans Fronteirs, 2003). ART also presents unprecedented opportunities for a more effective response by involving people living with HIV and AIDS, their families and communities in care and support. It enhances HIV prevention by increasing awareness, creating a demand for testing and counselling thus reducing the social stigma attached and discrimination. The following were the key research questions that anchored the study:

- i. What are reasons for joining the SGs?
- ii. What activities are carried out by SGs?
- iii. What organisations assist the SGs?



## LITERATURE/THEORETICAL UNDERPINNING

There are three social cognitive theories usually used to conceptualise the phenomenon of ART adherence. These are Health Belief Model, Theory of Planned Behaviour and the Social Network/Social Support Theories. The Health Belief Model (HBM) postulates that health-related action depends on following a particular health recommendation plan that is put in place, (Rosenstock, *et al*, 1988). The Theory of Planned Behaviour posits that the attitudes towards treatment adherence are as a result of a person's evaluative opinions, both positive and negative, (Ogden, 2010). In general, a positive attitude toward behaviour is associated with its practice while a negative attitude is negated, (Horne, *et al*, 2013).

The Social Networks/Social Support Theories draw their analysis on interpersonal behavioural aspects (Heaney, 2002). Most health programs today recognize the critical importance of the social environment and advocate changes in the social ecology, which is supportive of individual change leading to better health and a higher quality of life. However, within the community, long-term behaviour change depends on the level of participation and ownership felt by those being served. These social networks can be kin (extended family) or non-kin (church or work groups, friends or neighbours who regularly socialize clubs and sporting teams). Social networks have certain types of characteristics namely Structural, such as size (number of people) and Density (extent to which members really know one another), Interactional, which include reciprocity (mutual sharing), Durability (length of time in relationship), Intensity (frequency of interactions between members), and Dispersion (ease with which members can contact each other) and Functional, (ibid). Functional includes providing social support, connections to social contacts and resources, and maintenance of social identity.

Social support refers to the varying types of aid that are given to members of a social network. Research indicates that there are four kinds of supportive behaviours or acts namely Emotional support (listening, showing trust and concern), Instrumental support (offering real aid in the form of labour, money, time) Informational support (providing advice, suggestions, directives, referrals) and Appraisal support (affirming each other and giving feedback). This social support is given and received through the individual's social networks. However, some network ties may not offer adequate supportive ties (Horne, *et al*, 2013).

This study draws on the Social Networks/Social Support Theories in its empirical analysis. The study argues that contextual knowledge on SGs and the ART programme, the challenges they face is vital in the fight against the HIV and AIDS epidemic. Adherence to the ARVs is important. Adherence can be defined as a patient's ability to follow a treatment plan, taking medications at prescribed times and frequencies, and following restrictions under the plan. Inadequate adherence to treatment is normally associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections and in overall poorer health outcomes.

Other notable barriers to optimal adherence, which may potentially be faced by patients on ART, include poverty, health illiteracy, perceived social support, substance abuse and stigma. Health illiteracy is a barrier to adherence amongst patients living with chronic illnesses, (Sullivan, *et al*, 1992). Some only consider medication as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention. Yet, the longer-term health consequences of non-adherence may be severe, as symptoms will inevitably develop and the



disease will progress unchecked, (Pradier *et al.*, 2006). Social Support for Adherence is the encouragement from family and friends for the patient to co-operate with the recommendations and prescriptions of a health professional (Di Matteo, 2004).

## **MATERIALS AND METHODOLOGY**

### **Research Design**

The study utilized a case study research design. A case study is an in-depth exploration, often undertaken over time such as a policy, programme, intervention site, implementation process or participant (Goodrick, 2014). It was a comparative assessment of SGs in rural areas with those in the urban setup. It sought to find out which ones of the two fared better in terms of access to supportive services, the roles and challenges faced.

### **Sampling**

The participants were patients who belonged to SGs and were on ART registers at St. Anne's Brunapeg Hospital, and Plumtree District Hospital (for Mangwe). Stratified random sampling was used. St. Anne's Brunapeg Hospital and Plumtree District Hospital (for Mangwe) were each classed as strata. Only one clinic offers ART services in Nkulumane and this served as a strata. Nkulumane had eight SGs and Mangwe had six in total (2 at St. Anne's Brunapeg Hospital and four at Plumtree District Hospital).

### **Data Gathering Instruments**

Questionnaires and the FGDs were used in the inductive collection of qualitative data. Both of these instruments targeted those who were on the ART programme and belonged to an SG for PHLA.

### **Focus group discussions**

A total of Fourteen GDs were done (six SGs in Mangwe and the eight in Nkulumane). Each FDG averaged 30 minutes.

### **Questionnaires**

On average each FCGs consisted of eight members. Fourteen FDGs interviews were carried out. After that, the individual members individually filled out the questionnaire. The researchers guided and provided clarity. Participants present during their monthly district meetings filled One hundred and six questionnaires.



## RESULTS/FINDINGS

Thematic analysis was employed. Categories of data were grouped into themes, guided by the research questions. The following were the overriding themes that emerged from the qualitative discourse analysis.

### Data analysis and presentation on the questionnaires.

The OI clinics and ART programme started in 2004 in Zimbabwe, and then scaled up in 2007. The first OI clinic was established at Mpilo Hospital and is the one that provided the training to most OI clinics staff in the country. The SGs in Nkulumane raised fears that they might collapse due to inadequate support from health workers and other service providers. They work in isolation with near absent supervision from the health workers. Thirty six percent of patients have been in the SGs for periods ranging from six to 10 years. These reasons for joining the SGs are as follows:

In Nkulumane:

- i. Sharing ideas on positive living
- ii. Self-help projects
- iii. Peer counselling
- iv. Assist each other on drug adherence
- v. Vocational training
- vi. Helping each other financially
- vii. Sharing information on ARVs

In Mangwe:

- i. Sharing lived experiences and ideas on positive living.
- ii. Helping each other financially, household chores, bereavements and in times of illness.
- iii. Sharing information on ARVs and uptake
- iv. Psychosocial support
- v. Sharing ideas on self-reliance

It was noted that psychological support was the paramount reason for PLHA in joining SGs. The patients shared ideas on ARVs and living positively. Income generating projects and ideas on the same are also generated using the SGs meetings as a platform:

In Nkulumane:

- i. Projects such as candle making, rearing of chickens, vegetable gardening and bead making
- ii. Peer education and counselling
- iii. Saving and lending schemes
- iv. Drama classes and clubs
- v. Bereavement fund and helping each other during illnesses and bereavement

In Mangwe:

- i. Chicken rearing and vegetable gardens
- ii. *Ukubaza* (carving home equipment)



- iii. Saving and lending schemes
- iv. Financial contributions for those in need to buy food, school fees and transport expenses when one is due for a clinical review
- v. Home visits, care and support

Nkulumane district has more activities, which are of benefit to the patients on ART. These activities assist in the provision of basic needs of the patients; they also provide psychosocial support and nutritional support. These form some of the basic needs for patients on ART. The patients raised concerns that most of these activities were self-initiated with no external support from the service providers and other stakeholders. The following organisations assist the SGs in the two districts.

In Nkulumane:

- i. The National AIDS council of Zimbabwe and Matabeleland AIDS Council (NewLife Centre) provide information on HIV and AIDS management
- ii. Zimbabwe National Network for People Living Positively provides administrative training, information and counselling
- iii. Help Germany and The Roman Catholic Church provide food
- iv. World Food Programme provides food packs
- v. Zimbabwe AIDS Network provides information, testing and counselling.

In Mangwe:

- i. UNICEF provides food and blankets
- ii. CARITAS provides food
- iii. Netherlands Youth provides stationery
- iv. National AIDS Council of Zimbabwe provides information and material
- v. IOM provides gardening fencing borehole tap (plumbing), tools and seeds
- vi. Matabeleland AIDS Council provides counselling
- vii. Zimbabwe National Network for People Living Positively provides administrative training, information and counselling
- viii. CARITAS provides gardening tools.

### **Data analysis and presentation on the FGDs**

Mangwe had few patients on the ART programme than Nkulumane. People initially join the SGs in order to get the pertinent and crucial information such as where to access the ARVs. After that, they gradually fail to attend SG meetings, as they would have been equipped with the necessary information. In Mangwe, the membership of SGs is low as the SGs were relatively new.

The major reasons for joining the SGs were psychological and social support, assisting each on drug adherence and to embark on income generating projects. The SGs helped to create a sense of community and togetherness and thus negating isolation. All of the SGs highlighted that SGs were joined by those leaving with HIV and the affected. In Nkulumane, they cited inadequate information on drugs especially when changing drugs/ treatment regimens as a challenge. They registered concern that at times they do not have access to cotrimoxazole from the OIs and have to buy from the pharmacies (which are expensive, as they are not subsidised).



SGs reduce the defaulter rate and assist in follow-ups. They rationalised that the SGs would have collapsed way back if they were not helpful. Respondents saw SGs as a means of communication and helped to mobilise the patients on ART especially during the outreach programmes. They viewed SGs as well organised and programmes become easy to implement.

Staff shortage was high in both districts. Most of SGs were not formally registered. They were some that were community based with no formal structure, however, some had formal structures in place. The main challenge identified was lack of capacity to disseminate correct information pertaining to HIV and AIDS. This had negative implications on the ART programme as it created fear in some of the patients.

## DISCUSSION

Most SGs in urban areas have received a lot of support from funders. Results indicate that UNICEF, Netherlands Youth and CARITAS have given limited support to rural-based SGs. Out of the three SGs in the rural areas, which participated in this research, only one is being assisted by three organisations namely UNICEF, Netherlands Youth, and CADEC. The challenges faced by SGSs in Nkulumane include the lack of support (financial and technical for the projects), descent accommodation, up to date information with regard to the ART programme, experienced trainers to conduct workshops, the skills deficiency and burn out due to repetitive activities. In Mangwe, the SGs lacked financial support, inadequate water for households use and for the nutritional gardens. Transport facilities to enable visits to sick members were also a challenge and they are fewer men in the SGs. This echoes Madiba and Sigaga (2012) study that used a sample of men accessing antiretroviral treatment (ART) from a HIV clinic in South Africa. The intent was to examine their perceptions of SGs and explore their reasons for non-participation in such groups. The main barriers for non-participation related to issues on support groups were; namely unavailability of support groups in local communities including; no access, the timing of meetings and lack of transport money. The lack of transport was also cited by Olga (2012) study on perceived barriers to participation in SGs among People Living with HIV and AIDS, in Katlehong Township, South Africa. Another barrier raised was the fear of unintended disclosure of HIV status due to breach of confidentiality with resulting stigma and social rejection. On a personal level, some of participants felt that they had adequate support at home (ibid). Thus, they would consider participating if men only SGs were initiated, held on weekends, and are provided with more information on SGs. Madiba and Sigaga (2012) recommend that SGS group planners should consider men only SGs which has been shown to have positive outcomes and facilitates member participation. Similarly, in Kakamega County Referral Hospital, Kenya a youth-only WhatsApp group was formed so teens and young adults could discuss issues common among this age group. The group is open to young people living with HIV aged between 13 and 22 years (Abwao, 2017). As such, one could recommend that SGs in Mangwe and Nkulumane districts of Zimbabwe should perhaps take into account gender and age.

In most instances, SGs work alone with little to near absent supervision by health workers. Health workers cited work commitments due to acute staff shortages. Their absence from the SGs meetings could be partly attributed to the fact that the National AIDS Policy in Zimbabwe does not place much cognisance on SGs. They are no apparent guidelines in place on the involvement of the health personnel in SGs. Stigmatisation remains one of the biggest





challenges facing those living with the disease (also see Varni *et al.*, 2012; Turan, *et al.*, 2017). Shunned by their communities and even families, some say they are finding solace in SGs. One patient mentioned that other people still call them names like “*izitofu, abantu abasehlelweni*” and overhear remarks such as “*angikhulumi lomuntu osehlelweni*” (I do not talk to somebody on the ART programme). As such the stigma attached to HIV and patients on ART programme prevents people accessing HIV testing, care, support, treatment and prevention (International HIV/AIDS Alliance, 2005). Indeed, stigma and discrimination remains a central concern/still pervasive in local communities (see Cloete *et al.*, 2010; Moradi *et al.*, 2012; Flickinger *et al.*, 2017). Gadgil *et al.*, (2018) and Toseland & Rivas (2014) posited that sharing experiences of stigma and memories of shame, guilt, and pain promoted a sense of camaraderie that mitigated the negative impacts of both felt and enacted stigma. Other challenges faced by patients on ART include adherence to the ART programme and alcohol abuse. Moradi *et al.*, (2012) qualitative study sought to identify the health-care problems of people living with HIV in Tehran and Kermansha. The study cited substance abuse as a barrier/problem.

Religious beliefs are another challenge as some may abandon ARVs in favour of the anointed artefacts given by some of the New Age churches. It was also unearthed that some women in instances fear their spouses as such do not go for HIV testing. HIV testing is a sensitive issue in the African family settings especially if it is a patriarchal family.

## IMPLICATION TO RESEARCH AND PRACTICE

The SGs are vital in the ART programme and are in need of funding support. Channelled fund implies adequate resources, which could emancipate the SGs in carrying out their work. Funding could ensure that there is dedicated unit of health workers put in place. This unit could offer guidance, supervision and support to SGs

## CONCLUSION

SGs play a crucial role in the ART programme. They provide psychosocial support and care thereby creating a sense of wellbeing and belonging to a community. The projects they carry out help in raising money for food, medical expenses, transport fares and the school fees for their dependant. This is helpful as most of them are not working and widowed. Staff shortages in health facilities is a challenge as the SGs at times need the support and guidance of medical experts. Lack of capacity within the health centres is a challenge. However, funding and technical support exists through NGOs and other relevant actors. SGs in Nkulumane have a comparative advantage. They have access to more facilities, as they are located in the urban area.

## FUTURE RESEARCH

Future research could assess role of the health workers in SGs in both districts. The findings from their lenses could enrich this study into a mutual synthesis of both horizons.



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