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# REPORT

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## 'We Are Like Sisters'

*'An investigation into support groups for African women living with HIV/AIDS in Edinburgh and Glasgow'.*

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## **Abstract**

Over the last decade, HIV/AIDS infection rates have increased particularly, within African settler communities in the UK, with women being disproportionately affected. However, the experiences of African women living with HIV/AIDS in the UK and the support networks they use in their management of this disease have been under-researched. This paper aims to address this research gap by examining formal support groups that have been established by the UK-based voluntary organisations, Waverley Care and Terrence Higgins Trust, specifically for African women living with HIV/AIDS in Edinburgh and Glasgow. As HIV/AIDS support groups are sometimes considered an alternative support network for helping people living with HIV/AIDS cope with the physical and emotional effects of the disease on their lives, the reasons behind why and how both organisations offer support to African female service users are evaluated. By focusing on the cultural backgrounds and personal experiences of the women accessing these groups, the study also examines the extent to which forming the support groups on both 'ethno-specific' and 'gender-specific' grounds is advantageous for them in managing their lives with HIV/AIDS.

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## **Note on References**

All interviewees are designated in the text by numbers in brackets (see the appendix) and all references that are titled Personal Correspondence denote information that was gathered via email communication.

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## 1. Introduction

### 1.1. Background: Research on African women living with HIV/AIDS in the UK

Since the late 1990s, there has been a growth of literature on the issue of HIV/AIDS within African migrant communities<sup>1</sup> and the experiences of Africans living with HIV/AIDS in the UK.<sup>2</sup> This is a reflection of the increasing HIV/AIDS rates within the African migrant population in the UK over the past decade (Scott-Clark and Levy, 2005). In terms of themes, these studies have looked at various topics, for example, the advocacy for HIV prevention (Fakoya *et al*, 2008), needs assessment for African migrants living with HIV/AIDS (Weatherburn *et al*, 2003) and the sexual behaviour of African migrants, including analysis of gender relations and sexual practices within African cultures (Kesby *et al*, 2003). However, these studies have tended to focus on both African men and women living with HIV/AIDS in the UK. Specific literature on African women living with HIV/AIDS has been minimal (Doyal and Anderson, 2005, 2006). Also, women having sex with women living with HIV/AIDS in African migrant communities in the UK have generally been under-researched compared with African men who have sex with men (AB-DGN, 2010).

In terms of themes in the existing women's literature, there are various similarities with the mixed gender studies, for instance, HIV/AIDS prevention for women (WAND, 2005) but there have also been some alternative discussions such as women's education and employment needs from a gender-based perspective (Chakanyuka, 2005/06). In general, the majority of the literature on this topic tends to be in the form of qualitative studies focusing on evaluating the experiences of these women in managing life with HIV/AIDS and the issues they face because of their gender, seropositivity and legal status in the UK.<sup>3</sup> This is because qualitative investigations are best for gaining insight into 'sensitive issues'<sup>4</sup> (Mayoux, 2006:120) and to acquire a deeper understanding of the researched as it provides them with the opportunity 'to discuss things they have never been able to tell anyone before' (Mayoux, 2006: 122).

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<sup>1</sup> This constitutes communities that have been formed and are occupied by those who have emigrated from any country in the African continent.

<sup>2</sup> See McMunn *et al*, 1997, Erwin and Peters, 1999, Dodds *et al*, 2004 and Sinyemu and Baillie, 2005.

<sup>3</sup> See, for example, Doyal and Anderson, 2005, 2006 and McLeish, 2002.

<sup>4</sup> See 1.5.3. Ethical Review

This dissertation also takes the form of a qualitative study<sup>5</sup> to add to the existing literature, evaluating the support networks used by African women living with HIV/AIDS in the UK by focusing on formal support groups<sup>6</sup> established and used by them in Scotland. In facing women living with HIV/AIDS within the African migrant population in the UK, it will try to assess whether support groups are relevant to the lives of people living with HIV/AIDS (PLWHA) and if so, why. During my research period, I was able to work as a research intern at HIV Scotland, a leading HIV policy charity. This research topic resulted from an interest I developed in the organisation's African and Minority Ethnic HIV Project which aims to engage with PLWHA in Black Minority Ethnic communities in Scotland within policy and service provision. However, as part of this project, there was a lack of enquiry focusing on African women living with HIV/AIDS in Scotland and I felt that this research gap needed to be addressed. As an African woman myself, I was interested in investigating and learning about these women's experiences of and opinions about the support services they were provided with, and if their ethnicity, cultural background and gender had been taken into account within such interventions.

## **1.2. Support groups for African women living with HIV and AIDS**

'Support groups present information, provide comfort, teach coping skills, help reduce anxiety, and provide a place for people to share common concerns and emotional support' (American Cancer Society, 2011). In the UK context, formal support groups have been established specifically for African women living with HIV/AIDS but only in areas with significant African populations within the local context (1). These support groups have also generally been formed based on categorisations of gender and ethnicity.<sup>7</sup> Although fewer support groups are now available due to funding cuts to HIV services, they are widely accessed by African women living with HIV/AIDS (Winnie Ssanyu-Sseruma, Personal Correspondence).

In response to the stigma associated with the disease, many African women living with HIV/AIDS 'often suffer in silence because of their fear of rejection and discrimination' (Visser

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<sup>5</sup> As Mayoux (2006:123) states 'wherever possible, most research will use an integrated methodology'. Thus, a quantitative research method in the form of self-completed questionnaires was also used to gain essential factual background data and to seek out potential interviewees for the research.

<sup>6</sup> 'Formal' HIV/AIDS support groups are defined as those established through voluntary organisations, in comparison to those created informally as social and discussion groups by the members themselves.

<sup>7</sup> In my research, I failed to come across African support groups in the UK that were categorised by sexual orientation and could be accessed by women.

*et al*, 2005:334). This tendency to isolate themselves emotionally can lead to hopelessness and dejection (Phillips, 1998) and even self-removal from society (Dodds *et al*, 2004). However, Roth and Nelson (1997) argue that increased interaction with others going through similar experiences can help overcome these issues, and African women living with HIV/AIDS therefore access support groups as they provide an environment where they can share their emotions and experiences in living with HIV/AIDS with their peers (Krabbendam *et al*, 1998). Such, support groups allow these women to overcome societal isolation and 'provide them with a sense of belonging' (Liamputtong *et al*, 2009:6).

In addition, support groups can help women who are newly diagnosed to come to terms with their status as they 'offer the best hope for women' to 'live positively with HIV' (Page, 2000). Support groups can also help African women living with HIV/AIDS deal with the difficulty of disclosure, as well as offering an 'alternative' source of support for women who are not able to disclose their status to their family and friends (Dodds *et al*, 2004). In addition, they provide an environment where women can discuss their sexual and reproductive health and rights, care and medical treatment (Bell *et al*, 2007) and therefore become 'empowered' through knowledge that can benefit their health (2). Onwumere *et al* (2002:62) argue that empowerment through guidance on improving physical health is particularly important for HIV+ women as they are often found to experience incessant 'episodes of low self-worth and self-esteem', due to the effects that HIV/AIDS can have on their physical health. This can deter them from carrying out their domestic chores and childcare responsibilities (Lea, 1994). Therefore, there has been significant praise for the formation of support groups for PLWHA as 'the implementation of structured support groups takes the focus of providing support a step further, in providing coping skills and empowerment through knowledge' (Visser *et al*, 2005:335).

On the other hand, support groups have been argued to have drawbacks despite offering an effective support network for African women living with HIV/AIDS. Firstly, support groups for Africans with HIV/AIDS tend to have a short life-span because 'stigma and discrimination often get in the way' (3) as women fear 'indirect disclosure' if they are seen accessing HIV services (Fakoya *et al*, 2008:23). Furthermore, support groups are often not accessed by women who are in denial about their status as support groups require disclosure to the other members (Ssanyu-Sseruma, Personal Correspondence). Nonetheless, support groups can still be considered beneficial for African women living with HIV/AIDS because they encourage social isolation to be overcome through peer support, empowerment through

knowledge and the provision of a safe environment where disclosure is guaranteed not to be met with stigma and discrimination (2).

### **1.3. Research Topic**

This dissertation investigates formal support groups that have been established specifically for African women living with HIV/AIDS in Edinburgh and Glasgow. Firstly, it determines why and how the chosen voluntary organisations, Waverley Care and Terrence Higgins Trust (THT) offer support to African female service users through support groups. Secondly, the African women's support groups are evaluated within a 'developmental' framework to determine how they operate in offering support to service users. Lastly, the extent to which forming these support groups on an ethno and gender-specific basis is beneficial for the women's experience of these support groups and in managing life with HIV/AIDS is assessed. In doing this, the research addresses a set of specific questions:

- 1) Why and how did Waverley Care and Terrence Higgins Trust establish support groups specifically for African women living with HIV/AIDS?
- 2) How do these African women's support groups operate within a developmental framework to assist female service users?
- 3) What are the advantages and disadvantages for the female service users of forming ethno and gender-specific support groups?

### **1.4. Organisation of the Study**

Chapter two provides a review of the literature. It begins by evaluating the social, economic and political factors that determine why women migrate from Africa to the UK and the context of their lives in the country. It then analyses the reasons for increasing HIV/AIDS infection rates within the African migrant female population and the effects this has had on British HIV services and how the disease is perceived within African migrant communities and wider British society. Lastly, it evaluates the support networks used by African women living with HIV/AIDS and the existing research gap regarding African women's support groups in the UK.

Chapter three and four are based on the data collected, which form the research findings. Chapter three begins with the reasons for Waverley Care and THT establishing their African women's support groups. The African women's support groups are then analysed within a developmental framework to assess how they function and provide support to service users. By using a developmental framework, it can be established if the support groups use a 'top-down' approach, in which the group meetings are organised and led by the group facilitator on behalf of the group, or a 'bottom-up' approach, where the group meetings are instead planned and run by the female service users or, if a combination of both approaches are used.

Chapter four then assesses the extent to which the use of an ethno and gender-specific structure in forming the support groups is beneficial for African female service users in their support groups and for managing their lives with HIV/AIDS in a country that is not their homeland.

The concluding chapter provides a summary of the key points in the research findings and suggestions for future research that could contribute to the existing literature on African women living with HIV/AIDS in the UK.

## **1.5. Research Methodology**

### **1.5.1. Introduction**

This dissertation is partly based on research conducted on three African women's support groups in Glasgow and Edinburgh between May and July 2011. The facilitators of the support groups and the female service users were the main participants of the research. Firstly, it was pivotal for this research to consult with the group facilitators who were essentially the 'gatekeepers'<sup>8</sup>, as they had a strong rapport with the service users, facilitated each group meeting and had knowledge of their group's history and operation. Secondly, the female service users were the target group of the investigation and it was essential to formulate research questions that would gain first-hand accounts of their experiences of managing life with HIV/AIDS and being in an African women's support group.

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<sup>8</sup> Gatekeepers can be described as the 'individuals in an organisation that have the power to withhold access to people or situations for the purposes of research' (Miniechello *et al*, 1997 in de Laine, 2000:123).

### 1.5.2. Case Studies

For this dissertation, I decided to use a case-study approach because I felt it was the most suitable for the analysis and evaluation of support groups for PLWHA, as McGregor (2006:201) comments that this method may be used 'to assess the need and feasibility for a particular type of intervention'.

The African women's support groups investigated were established by Waverley Care and the THT. Waverley Care was established in 1989 and since its inception, has been one of Scotland's leading charities providing care, assistance and support to people living with HIV/AIDS and Hepatitis C (Waverley Care, 2011a). Like Waverley Care, THT is long established and since its creation in 1982 it has become one of the UK's leading HIV and sexual health charities (Terrence Higgins Trust, 2011a).

Waverley Care and THT were chosen as the case study organisations because both can fairly be considered the main service providers for Africans living with HIV/AIDS in Scotland (4) (Souley *et al*, 2011). Both organisations provide various outreach networks for PLWHA in African communities across Scotland and support groups have been formed as part of these interventions. Another advantage of using these organisations as case studies, as will become evident, is that each has a different approach in the operation of their support groups. In total, the dissertation investigates two African women's support groups established by Waverley Care, in Edinburgh and Glasgow, and one set up by THT in Glasgow.

The Waverley Care African women's support groups in Edinburgh and Glasgow meet once a month. The group in Edinburgh has been running for four years and the majority of members are in their thirties, though some are also in their twenties and forties (Marion Chatterley, Personal Correspondence). The nationalities of the current members are Malawian, Zambian, Nigerian, Ugandan and Tanzanian (Marion Chatterley, Personal Correspondence). The support group in Glasgow has been running for the past three years and the members range in age from late twenties to mid-fifties (5). The nationalities of the current members of this support group are Zimbabwean, Malawian, South African, Nigerian, Eritrean, Congolese, Kenyan, Somali, Ugandan and Kenyan (5).

The THT group has been running for over a year. The group meets every fortnight and has fifty members (6). Service users in this support group have an age range from early twenties

to mid-forties and the majority are from countries in Southern and Eastern Africa such as Zimbabwe, Malawi and Zambia, but there are also a few from West African countries such as Nigeria and Liberia (6).

### **1.5.3. Ethical Review**

The investigation was based on research that could be categorised as 'sensitive' (Lee, 1993). HIV/AIDS is a disease that has been highly stigmatised and therefore engaging with PLWHA required me to take a perceptive and cautious approach (Cree, 2008). As 'ethical concerns must always be an integral and planned element in research design' (Mayoux, 2006:123), it was essential for the research proposal and methodology to go through an ethical review process.<sup>9</sup> The proposal and methodology passed the self-audit checklist for Level 1 and the study was sanctioned by the University of Edinburgh's School of Social and Political Studies Research Ethics Committee in April, 2011.

### **1.5.4. Research Methods: Questionnaires**

Guided by Pratt and Loizos (1992:62) who advise that 'surveys are useful for obtaining factual or attitudinal information', self-complete questionnaires were distributed to the members of both the Waverley Care and THT support groups in order to acquire factual information about their background, including ethnicity, nationality, age and marital status. This was done with the aim of drawing up the personal background of the women in each group and also to request if they would like to be contacted for a follow up interview.<sup>10</sup> To take part in the study, the service users had to be HIV positive, African, female and live in Scotland.<sup>11</sup> However, it was emphasised that completing the questionnaire and taking part in a follow-up interview were voluntary, as Willis (2006:147) argues that 'for ethical reasons, you should always try to ensure that individuals can refuse to take part in the research'.

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<sup>9</sup> Since this research was sensitive in nature, it had to be ensured that no harm was caused to the service users emotionally and thus the interviews had to be conducted in a safe environment where they felt comfortable. Anonymity was also guaranteed for the service users at all stages of their participation in the research and the same was offered for the group facilitators. However, the latter were all happy to be referenced by name in the dissertation.

<sup>10</sup> See 1.4.7: Research Challenges.

<sup>11</sup> In taking guidance from Forsyth *et al* (2005), in referring to 'Africans' in this case, the term means those who were born in any African country.

Details about my background as a student and the purpose of the research were provided on the questionnaires. This was required to obtain 'informed consent' (Brydon, 2006:26), as the service users had to be made aware of the research objectives. My nationality and gender were also provided as I felt that my 'positionality' (Binns, 2006) as a black African woman would influence the service users' decision to take part in the research. Lastly, a guarantee that all the information would be destroyed after the completion of my research was included and it was made clear that if respondents agreed to be interviewed, they would remain anonymous.

#### **1.5.5. Research Methods: Interviews**

To collect the data, the main research method used was semi-structured interviews. This was the most appropriate method for the investigation as I wanted to ensure that the most important themes were not only addressed but the questions 'also provided the interviewees with opportunities to bring up their own ideas and thoughts' (Willis, 2006:145).

I contacted all the service users who agreed to an interview and used this opportunity to discuss the research objectives further and arrange a time and date for the interview. Both the group facilitators and service users were given a choice of interview location to ensure it would be a place where they felt comfortable. All the interviews with the group facilitators and service users took place in the head offices of Waverley Care and THT apart from that with one service user which took place at Milestone, a respite centre for PLWHA owned by Waverley Care in Edinburgh.<sup>12</sup>

The group facilitator of each support group was interviewed, making three in total. The interviews with the group facilitators lasted average of an hour. Two of the interviews were followed up by a telephone interview at a later date. Both lasted thirty minutes. One of the preliminary interviews was tape recorded with the interviewee's permission and was later transcribed. During the other interviews with the facilitators, handwritten notes were taken because the transcription of the taped interview was quite time consuming and as Willis (2006:150) highlights 'taking notes during the interview may be an appropriate compromise'. Eight service users in total were interviewed, five with service users at THT in Glasgow, two with service users in Waverley Care's support group in Glasgow and one with a service user in Waverley Care's support group in Edinburgh. All the women identified themselves as

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<sup>12</sup> This interview took place on a visit I made to the centre as part of my research.

black African. Four women were from Zimbabwe; the other four were Malawian, Liberian, Nigerian and Gambian. Of those questionnaire respondents who gave their age, the youngest was 31 and the oldest was 57.<sup>13</sup> Seven of the women had children living in the UK or in their home countries. The interviews with the service users lasted on average between 15 and 25 minutes and there were no follow-up interviews. None of the interviews with service users were tape-recorded and all notes were handwritten. In addition, to the questionnaires and semi-structured interviews, I spent time with the interviewees in the support groups outside their meetings on various occasions to better understand and observe their interaction.<sup>14</sup> During this time, I was able to ask the service users questions on a more informal basis (Cree, 2008).

Each service user who participated in the interviews was given a ten pound shop voucher as a token of gratitude. I felt the distribution of vouchers to interviewees was justified because the majority of these women were unemployed or experiencing severe economic difficulties (6).<sup>15</sup> The vouchers were funded by my internship organisation, HIV Scotland.<sup>16</sup> At the end of the interviews, both the facilitators and service users were asked if they had any questions and if they would like a copy of the research findings.

#### **1.5.6. Research Challenges**

Originally, when deciding on the research methodology, I aimed to attend the support group meetings in Edinburgh and Glasgow, sitting in as an 'observer', carrying out background questionnaires and arranging future one-to-one interviews with any of the female service users who were happy to take part in the research. However, the group facilitators did not feel comfortable about me attending their support group meetings, mainly because they were understandably protective of their service users and there was a general consensus amongst the women in all the support groups, that they did not feel comfortable with an

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<sup>13</sup> Completing the questionnaire was a requirement before being interviewed. When service users are referred to in the appendix where they did not give their age in the questionnaire this is indicated as N/A.

<sup>14</sup> I visited the Milestone respite centre twice in June, 2011 for a meeting about welfare benefits and for a mixed women's support group meeting. I also attended Waverley Care's Christian Faith and Health Conference in Glasgow in July where some service users were present.

<sup>15</sup> This procedure has often been used in social science research; for example, in Cree's research on Waverley Care's HIV awareness campaign for Africans living in Glasgow in 2007, all the informants who were Africans based in the local area were paid £20 in expenses for taking part in the research (2008:14).

<sup>16</sup> HIV Scotland has a policy of reimbursing certain expenses for their interns including travel and other justified expenses incurred during the research.

'outsider' attending their group meetings.<sup>17</sup> Therefore, I had to consider my 'reflexivity' (Momsen, 2006) as a researcher because although I shared the same ethnicity and gender as the women, these commonalities were not enough to make them feel comfortable in allowing me access into the group fold. At the same time, this setback also encouraged me to be more aware of the issue of confidentiality at all stages of the research because of these women's fear of HIV/AIDS-related stigma and discrimination (Fieldwork note, May, 2011, Edinburgh and Glasgow).

The dual effect of the setback was that I would not gain the accessible position of being able to organise one-to-one interviews as a result of participant observation in the group meetings, while also losing out on any insights that may have been gained from the meetings themselves. To overcome this research obstacle, alternative channels to locate female service users willing to participate were taken. Therefore, as previously expressed, interviewees were recruited via the self-completed questionnaires.<sup>18</sup> 'Snowballing' (Willis, 2006) was used to meet female service users who were or are currently members of women's support groups in Scotland, by enquiring through HIV Scotland and through contacts that I had made during my research, such as the African Health Policy Network. Eventually, I was able to gain the majority of my interviewees via the group facilitator at THT who set up interview slots with several of their service users.

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<sup>17</sup> 'Outsider' in this context is one who is not HIV Positive. I believe this mind-set is related to existing HIV-related stigma, fear of judgement from others and of disclosure of their status to the wider public (7) (8).

<sup>18</sup> The interviews with the two service users in the Waverley Care support group in Glasgow were organised via the questionnaires.

## 2. Literature Review

### 2.1. Introduction: The African Diaspora

The term diaspora has been defined and interpreted in various ways since its original association with the 'Jewish dispersion' to the extent that there is no single definition of the term that is universally accepted (Akyeampong, 2000:184). However, if we take the following definition from Clifford as a guide, the 'diaspora articulates, or bends together, both roots and routes to construct (...) alternate public spheres, forms of community consciousness and solidarity that maintain identifications outside the national time/space' (1994:308). The African Diaspora can therefore be defined as a 'triadic relationship linking a dispersed group of people to the homeland, Africa and to their host or adopted countries' (Harris, 1996:7). The African Diaspora originated from 'the voluntary and involuntary movement of Africans to various areas of the world since ancient times' (Jalloh, 1996:3). As Akyeampong clarifies, it was the 'forced migration of Africans' through the slave trade that was the basis of the African Diaspora before the start of the nineteenth century (2000:213). However, since the beginning of the twentieth century, the African Diaspora, also known as the 'new' diaspora, has been redefined as a 'voluntary' migration 'on a global scale' (Akyeampong, 2000:213).

Since the start of the twentieth century, prosperous Africans 'have been sending their children to be educated in the UK' (Othieno, 1998:28). However, during successive decades following the 1950s and 60s, the process of the African continent's de-colonisation began to greatly influence many Africans' destinations of choice. Former colonial links between many European and African countries have made 'European cities an obvious destination for migrant Africans (McMunn *et al*, 1997:157). During the 1950s and 60s, the flow of migrants within the British Commonwealth was dominated by Ghanaians and Nigerians who began to migrate to the UK to settle (Scott-Clark and Levy, 2005). However, by the 1970s and 80s, many Africans from Somalia, Ethiopia and Angola began to immigrate to the UK to escape conflict in their home countries and seek political asylum (Scott-Clark and Levy, 2005; Othieno, 1998). By the 1990s, a new wave of migrants from Uganda, Zambia and Zimbabwe began to arrive in the UK (Scott-Clark and Levy, 2005).

Although, the common perspective is that the majority of African men and women come to the UK to seek asylum and escape conflict or gender-based persecution (Doyal and Anderson, 2005; Waverley Care, 2011b), there are in fact various reasons behind why

African women choose to migrate to the UK. Many African women immigrate to the UK to pursue educational opportunities and to be reunited with family members, known as 'chain' migration (9).<sup>19</sup> Sex trafficking has also been an unfortunate but common reason behind the migration of many African women who have been led to believe that they are to receive 'good jobs' in the UK (Akyeampong, 2000:188). However, labour opportunities are generally accepted as being the primary reason why African women migrate to the UK as Hosanna Bankhead (2) argues that poverty is a 'push' factor for many women as they try 'to make a livelihood to support themselves and their families'. Migration for labour is also evident in the current 'brain-drain' of African academics and professionals to countries in the West (Akyeampong, 2000).

Yet, for many African migrant women living in the UK, especially those who are mothers, economic difficulties, inadequate housing and racism form continuous impediments in their everyday lives (McLeish, 2002). African women who apply for asylum in the UK are entitled to income support from the National Asylum Support Service, but cannot be legally employed (Prost, 2005). Women whose asylum applications have been denied and remain in the UK as 'over-stayers', often take on menial work that is illegal and often 'badly paid' (Dodds *et al*, 2004:12). However, even for those who have permission to stay in the UK, finding employment is difficult as 'people from minority ethnic communities are more likely than people from white communities to be unemployed or in employment which is not commensurate with their levels of education or skill' (Scottish Refugee Council, 2010:42). In addition, women who have escaped conflict in their home countries, may have had their education disrupted and therefore immigrate to the UK, illiterate or with little education, thereby damaging their credentials in the labour market (Othieno, 1998).

Such obstacles in the labour market can be problematic for African women in the UK because for some their 'primary responsibility' is to their families back home to whom they send remittances (Mercer *et al*, 2008:145, Chinouya, 2010). For African women who have left their children behind in their home countries, not being able to provide financial support exacerbates what is already a sensitive dilemma, as Levitt and Jaworsky (2007:138) emphasise that 'transnational motherhood takes a toll', especially as 'care-giving at a distance is emotionally stressful for parents'.

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<sup>19</sup> This is the 'movement in which prospective migrants learn of opportunities, are provided with transportation, and have initial accommodation and employment arranged by means of primary social relationships with previous migrants' (MacDonald and MacDonald, 1964:82).

For African women who seek asylum in the UK, accommodation is also provided by the National Asylum Support Service. However, the accommodation is often criticised as being of a poor standard (Sinyemu and Baillie, 2005) and the common 'shared' housing arrangements have also been disparaged as the conditions are often cramped and the lack of privacy has been criticised as it makes 'it difficult' for women 'to live free lives' (Mildred Zimunya, Personal Correspondence). Furthermore, cultural dissimilarities are common, with many African migrants finding it difficult to integrate into wider British society (Souley *et al*, 2011). In a study that looked at the social experiences of seventy-five African migrants living with HIV/AIDS in various parts of the UK, it was concluded that 'most find themselves on the periphery of British social life, their survival depending on the support of other African people or charitable Britons' (Dodds *et al*, 2004:9).<sup>20</sup>

## **2.2. African women living with HIV/AIDS in the UK**

Despite African women migrating from their homelands in search of safety, better opportunities or to be reunited with relatives, their life in the UK is often difficult in terms of securing financial security, good housing and managing cultural differences in that they may face racism and discrimination (Weatherburn *et al*, 2003; Dodds *et al*, 2004). Moreover, due to the increasing HIV/AIDS infection rates within both sub-Saharan Africa and amongst African migrants in the UK, in recent years, significant attention needs to be given to how HIV/AIDS affects African women and HIV services in the UK, as well as social discourses on the disease in African migrant communities and within wider British society.

By the end of the 1990s, with the number of Africans immigrating to the UK greatly increasing and the HIV/AIDS epidemic in sub-Saharan Africa<sup>21</sup>, African migrants in the UK were considered to be at great risk of being infected with the virus (Scott-Clark and Levy, 2005). In 1999, when the number of HIV infections amongst Africans overtook those amongst gay and bisexual men 'for the first time' (Scott-Clark and Levy, 2005)<sup>22</sup>, concerns were raised over public health in the UK. Although, in comparison to some parts of the world, the HIV/AIDS epidemic in the UK is minimal (AVERT 2011a), the number of HIV positive Africans accessing HIV services in the UK increased from 4,920 in 2000 to 23,290 in 2009

<sup>20</sup> Forty-one of the participants were women (Dodds *et al*, 2004:5)

<sup>21</sup> Sub-Saharan Africa is the most affected part of the world for the spread of HIV/AIDS. By the end of 2009, it was estimated that 22.5 million people were living with HIV in this part of the African continent (AVERT, 2011b).

<sup>22</sup> Traditionally, homosexual men have been 'the group most affected by HIV in the UK' (Terrence Higgins Trust, 2011c).

(NAT, 2011). The high HIV/AIDS infection rates in African communities in the UK continue to cause concern in relation to the country's public health, and Fakoya *et al* (2008:23) appropriately describe the situation as one in which 'the face of the HIV epidemic' in the UK is starting to reflect 'patterns of disease in sub-Saharan Africa'.

African women have been more greatly affected by HIV/AIDS than men. By 2009, it was estimated that around two-thirds of Africans living with HIV/AIDS and accessing medical care were female (NAT, 2011). This is the trend in both the UK and Africa where more women are generally diagnosed with HIV/AIDS than men (Prost *et al*, 2008). As far as the reasons for this are concerned, in recent years, more African women in the UK have accessed voluntary confidential antenatal HIV testing (Prost, 2005). Gibb *et al* (2004) argue that this has revealed diagnoses amongst women and therefore prevented future mother to child transmission, but at the same time it has increased the number of diagnoses amongst women, while possibly indicating under diagnosis in men (Weatherburn *et al*, 2003).

Heterosexual sex is the most common route of HIV/AIDS transmission to African women (Prost *et al*, 2008) and women are more vulnerable to infection because of their biological predisposition (Weatherburn *et al*, 2003). Women are also more susceptible to infection because of their social status within the African cultural context. Culture 'remains one of the greatest constraints on the enjoyment of women's human rights in Africa' (Kissakye, 2002:209), as many African societies have a system of patriarchy that greatly subordinates women in terms of sexual practice. Women accordingly often do not have the right to negotiate condom use and determine sexual activity in male-female relationships and are therefore more vulnerable to infection if their partner has several sexual partners at one time and does not practice safe sex; which are social norms usually associated with African men (UNFPA, 2004b).

Regarding the effect that this increase in HIV/AIDS infection rates amongst African female migrants has had on HIV services, as recently as May 2011, funding for HIV services in the UK has been reduced (Dangerfield, 2011). This has led to a situation in which the increase in HIV infection rates amongst African women in the UK has led to greater numbers accessing services, putting considerable strain on HIV services that were 'already struggling to cope with (existing) numbers' (Ssanyu-Sseruma, Personal Correspondence). The British

government's dispersal policy<sup>23</sup> is another reason HIV services outside London being accessed by higher numbers of African women living with HIV/AIDS. However, since many of the HIV services outside London have found it difficult to cope with the increase in numbers of service users, the policy has been criticised for denying many asylum seekers living with HIV/AIDS access to the medical treatment that they need (Ssanyu-Sseruma, Personal Correspondence; BBC News, 2003).

Having established that HIV services in the UK are under pressure due to the increasing number of African women living with HIV/AIDS, it is now important to analyse how HIV/AIDS is perceived within African migrant communities and within wider British society. Stigma and discrimination are key terms associated with HIV/AIDS (Dodds *et al*, 2004). In the UK, HIV/AIDS-related stigma and discrimination is a prominent issue. Indeed, the perception encouraged by the media is that HIV/AIDS is a health issue more relevant to the regions of sub-Saharan Africa (Hayes, 2007). However, with the rise of infections within African migrant communities in the UK, this idea has now been applied to Africans living in the UK, who, as a consequence, experience what has been termed 'double discrimination', that is, discrimination based on race and on insinuated or confirmed HIV status (NAT, 2003). In Dodds *et al*'s study, among the Africans interviewed, it was reported that most 'felt that the majority of the British population believed that all African people have HIV or AIDS' (2004:15). The British media were also believed to have encouraged the belief that African migrants in the UK were 'responsible for 'importing' HIV to the UK' (Dodds *et al*, 2004:15).

On the other hand, in African migrant communities in the UK, the stigma that people associate with HIV/AIDS is strongly influenced by the existing mentality surrounding the disease in their home countries (BBC News, 2001b). Stigma surrounding HIV/AIDS in sub-Saharan Africa is primarily based on the belief that it is a 'death sentence' (Marsland, 2011), an incurable disease that without the necessary treatment will lead to a premature death. HIV-related stigma in the African context is also based on the knowledge that it is a sexually transmitted infection, which is particularly detrimental in African societies where issues regarding sexual practice are often 'cloaked in a heavy shroud of secrecy, shame, taboos, and silence' (Tamale, 2009:51).

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<sup>23</sup> Since 2000, the British government has enforced a policy of dispersal in which asylum seekers are relocated to other parts of the UK to reduce pressure on social housing in London and South-East England, lessen the financial costs on councils and hinder the influx of migrants who seek asylum in the UK (BBC News, 2001a).

For women, the situation is particularly bad as in many African cultures, the 'social and cultural values surrounding the importance of female purity' often means that African women living with HIV and AIDS 'are subject to greater discrimination than men' (Esplen, 2007:2).

For these reasons, disclosure of HIV status amongst fellow Africans in the UK can be very hard and for some it is never possible, especially as McMunn *et al* (1997:158) argue that the 'stigmatisation of HIV in African communities has been extremely powerful' and that the stigma surrounding HIV in African migrant communities in the UK can be considered greater than in countries in sub-Saharan Africa (Erwin and Peters, 1999). Doyal and Anderson bring the example of a woman from Zambia who commented that due to the stigma associated with women having HIV/AIDS in her community in the UK, it was very hard for her to disclose her status, as she commented 'even now, it is very hard to tell somebody I am sick, because like our community they take it as a curse, or like you misbehaved or went out with somebody, like they take you as a prostitute, it is an attitude which is very bad that we have' (2006: 100). Therefore, in taking guidance from Parker and Aggleton (2003), stigma towards HIV+ women in this case is not only based on their seropositivity but also on sexism.

### **2.3. Support networks for African women living with HIV/AIDS in the UK**

Due to the stigma associated with the disease, African women living with HIV/AIDS often isolate themselves from wider society (Chakanyuka, 2005/06) and, as previously stated, they tend to feel shame and low self-regard because of their seropositivity. According to a study of twenty-five Africans living with HIV in Edinburgh and Glasgow, African women 'tended to blame themselves' for their HIV diagnosis but the men 'tended to blame their partners or others' (Sinyemu and Baillie, 2005:1). However, some women do try to overcome this isolation and seek support to help them manage life with HIV/AIDS.

Firstly, friends and relatives<sup>24</sup> both in the UK (Dodds *et al*, 2004) and in their home countries (Chinouya, 2010) are highly regarded as a main source of support for African women trying to manage life with HIV and AIDS. In Dodds *et al*'s study, several women commented on how their friends and family in the UK were a source of practical support, especially when they were feeling unwell as one woman commented 'If I am not well, my family will care for my children' (2004:27). The female participants also stated that the support given by

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<sup>24</sup> Friends and relatives also include relationship partners.

relatives and friends provided a 'protective emotional and psychological boost' (Dodds *et al*, 2004:27).

There has been little research on the role of religion and spirituality in helping Africans living with HIV/AIDS in the UK (Ridge *et al*, 2008). However, what there is indicates that for African women living with HIV/AIDS religious faith has tended to provide them with an 'inner strength' in coping with the disease in their everyday lives (Doyal and Anderson, 2005:1737). This reliance on religious faith has been particularly encouraged by the growth of African religious communities in the UK (9). This has primarily been the result of the growth of African New Religious Movements which emerged in various parts of Africa from the late twentieth century.<sup>25</sup> In recent years, these movements have spread to various European countries including the UK where they have adapted themselves 'to new geo-cultural boundaries and non-African realities' (Adogame, 2008:296). Some Africans therefore come to the UK, primarily London, to establish African churches as part of the globalisation of these movements and many of these churches form the cornerstone of African migrant communities (9).

However, these various support networks are not always beneficial to African women with HIV/AIDS and they can be detrimental not only emotionally but also to their position in society and even their physical health. Firstly, gaining support from family and friends can be difficult because of the stigma associated with HIV/AIDS that is prevalent in many African countries. Due to HIV-related stigma and discrimination, some women who have disclosed their status to their families have been disowned (Chase and Aggleton, 2001). Some women have also reported being victims of gossip and discrimination within their local communities after disclosure (Chakanyuka, 2005/06) and in consequence, they can experience 'social death' (Dodds *et al*, 2004:20). Some women also experience partner violence and there have been accounts of women being pushed out of their homes by their male partners when they have disclosed their HIV status (Doyal and Anderson, 2005). Domestic violence can also prevent a woman living with HIV/AIDS 'from accessing treatment, thus potentially leading to infection of her children, death herself, and/or orphan status for her offspring' (Murray *et al*, 2006:615).

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<sup>25</sup> Examples of new movements include the African Pentecostal or charismatic churches and the African Instituted Churches (AICs) that have developed from traditional Christianity (Adogame, 2008).

Furthermore, difficulties have been reported for African women living with HIV/AIDS gaining support from their religious communities and churches as research shows that stigma and discrimination are advocated by some religious leaders (AHPN, 2009). Reverend Patricia Sawo from ANERELA + (African Network of Religious Leaders living with or affected by HIV/AIDS) argues that these leaders have been promoting a “fraud theology based on guilt” based on their teachings that HIV and AIDS are the result of promiscuity and inappropriate sexual behaviour (Waverley Care and Church of Scotland, 2006). Consequently, some women avoid the institutional church and rely on their own personal faith to help them cope with HIV/AIDS (Doyal and Anderson, 2005).

Although, the benefits and shortcomings of support networks sought by African women to help them manage life with HIV/AIDS have been evaluated in several studies, support groups accessed by African women living with HIV/AIDS in the UK have been given comparatively little attention in the literature. Overall, there has been minimal study of the interventions intended to provide support for HIV positive African women in this context (AB-DGN, 2010). Although, there is significant literature on women’s support groups based in sub-Saharan African regions, such as South Africa (Visser *et al*, 2005), Zimbabwe (Krabbendam *et al*, 1998) and Ghana (Russell, 2008), HIV/AIDS support groups have hardly been mentioned as part of support networks in the literature on HIV+ African women in the UK. For example, Doyal and Anderson (2005) only mention support groups briefly as a network used by HIV+ African women to socialise. However, within the women’s literature, there has been no in-depth study of support groups established specifically for African women living with HIV/AIDS in the UK.<sup>26</sup>

#### **2.4. Conclusion**

It is evident that African women living as migrants with HIV/AIDS in the UK can experience various difficulties due to their legal status, gender and seropositivity. However, the literature on these women remains nominal which is astounding in the light of the higher proportion of HIV/AIDS infections they account for within the African migrant population (Onwumere *et al*, 2002). The majority, if not all the existing literature, has also tended to focus on the African female population living with HIV/AIDS in London, which, on the basis of geographical focus,

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<sup>26</sup> Takura and Power’s (2002) research looking at support groups for African migrant women living with HIV/AIDS in Birmingham forms the exception.

makes the existing literature subjective.<sup>27</sup> In addition, there is no specific focus in the existing literature on formal African women's support groups, including how they operate to provide support, how they are experienced by women and how they help women manage HIV/AIDS in their daily lives. To address this gap in the literature, this dissertation focuses on formal support groups that have been created specifically for HIV+ African women in Scotland. Although the African population living with HIV/AIDS in Scotland is small<sup>28</sup>, there has been increasing research in recent years on PLWHA in African communities in the country (Sinyemu and Baillie, 2005, Souley *et al*, 2011; Cree, 2008). However, they are still under-researched (Souley *et al*, 2011). In addition, none of the existing studies conducted on Africans living with HIV/AIDS in Scotland have focused solely on HIV+ African women or on support groups for PLWHA.

The focus on women within the context of HIV/AIDS in this study is partly based on the rationale that women who live with the virus have gender-sensitive<sup>29</sup> issues and needs that warrant an independent investigation from men with HIV/AIDS (Lamping and Sewitch, 1990). In using African women's support groups as a case study, these issues will not only be disclosed but taking into account the cultural backgrounds of these women will determine 'how gender and gender inequalities shape attitudes, beliefs and experiences' in relation to HIV/AIDS (AB-DGN, 2010:4). As becomes evident in this dissertation, the issues addressed that specifically affect African women with HIV/AIDS in comparison to African men with HIV/AIDS are ones that can often affect all HIV positive women. However, it is important to take into account that one of the aims of this study is to gain insight into how HIV/AIDS is experienced within this specific 'female ethnic minority group' (Onwumere *et al*, 2002:63).

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<sup>27</sup> See Doyal and Anderson (2005, 2006), WAND (2005) and Chakanyuka (2005/06).

<sup>28</sup> According to the National AIDS Trust, in 2009, the percentage of Africans living with HIV/AIDS in Scotland was 3% compared to 95.4 % in England (NAT, 2011).

<sup>29</sup> A gender-sensitive approach can be defined as one which responds 'to the different needs and constraints of individuals based on their gender and sexuality' (Tallis, 2002:31).

### **3. Support groups for African women living with HIV/AIDS in Edinburgh and Glasgow**

#### **3.1. Introduction: Africans living with HIV/AIDS in Scotland**

The African migrant population in Scotland is relatively small. According to the 2001 Census, an estimated 10,000 Africans were living in Scotland with around half living in the capital city, Edinburgh (Souley *et al*, 2011:14).<sup>30</sup> However, within the last decade, the number of Africans migrating to Scotland has steadily increased, especially after Glasgow became a dispersal centre for asylum seekers in 2000 (6).<sup>31</sup> Traditionally, Africans who migrated to Scotland were students who went back to their home countries once they had completed their studies, but many Africans migrating to Scotland in recent years have sought permanent residence in the country (6). This led Souley *et al* (2011:18) to declare that 'Scotland has a growing population of African communities'.

As previously expressed, in Scotland, HIV/AIDS infection rates are very low especially in comparison to the rest of the UK. In 2010, Health Protection Scotland stated that there were 6,534 people living with HIV in Scotland (Souley *et al*, 2011:20). However, 18.9% of total infections were amongst Africans (Souley *et al*, 2011:20). Therefore, although the African population in Scotland is small, they constitute a significant proportion of the country's HIV/AIDS infection rates. In the past, due to the large African population in Edinburgh, the majority of Africans living with HIV/AIDS in Scotland were based either there or in the surrounding Lothian area but in recent years, since becoming a dispersal centre, there has been an increase in HIV infection rates amongst the African population in the Greater Glasgow area (Waverley Care and Church of Scotland, 2006).

Consequently, Scotland's HIV services provide interventions to cater for this population within major cities such as Edinburgh and Glasgow (1), although, there is criticism that not enough is being done in terms of service provision. For example, Souley *et al* (2011:18-19) argue that 'some charities have specific programmes designed to meet the needs of African communities but these are in the minority'. However, service provision for PLWHA in the

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<sup>30</sup> This number is small particularly in relation to the total population of Scotland, which in mid-2010 was 5,222,100 in number (The Scottish Government, 2011).

<sup>31</sup> In 2001, figures from the Home Office showed that over 25,000 asylum seekers had been transferred to other areas of the UK through the dispersal system (BBC News, 2001a). Glasgow received the highest number with 3137 asylum seekers relocating there that year (BBC News, 2001a).

country's African migrant population is a difficult task as 'Africans living with HIV in Scotland are marginalised and hard to reach' (7).

### **3.2. Waverley Care's African women's support groups**

Waverley Care aims to overcome this problem and provide support for Africans living with HIV/AIDS within the local context. The charity has established itself as one of the main service providers for Africans living with HIV/AIDS in Scotland as it recognises 'that Africans affected by HIV/AIDS frequently have a range of needs, as well as cultural differences, which make their situation unique in Scotland' (Waverley Care, 2011c). This forms the rationale behind its African Health Project which aims to provide 'a number of services relating to HIV in Scotland including support to African individuals living with HIV and awareness amongst African communities' (Waverley Care, 2011c).

The African women's support group programme based in Edinburgh and Glasgow is one of the support interventions provided through the project. The support groups are intended to meet one of the project's aims, which is to provide information about HIV/AIDS for service users and a social space for them to discuss this information (10). These support groups are unique in that they are solely for women, although the organisation has also established an African mixed gender support group in Glasgow. Waverley Care's African women's support groups are one of three projects that the Church of Scotland funds in Scotland (Church of Scotland, 2011), and the funding covers costs of meals, travel and social activities for the service users (7). One of the characteristic positive contributions made by churches and faith groups in trying to combat the HIV/AIDS epidemic is their provision of food and material support for PLWHA (AHPN, 2009; Ridge *et al*, 2008).

Although Waverley Care's African women's support groups are part of its African Health Project, the groups in Edinburgh and Glasgow were established through different circumstances though both in response to African female service users' needs. These groups also operate differently despite some similarities in group structure.

### **3.2.1. Waverley Care African women's support group: Edinburgh**

The African women's support group set up by Waverley Care in Edinburgh was initiated by existing service users who were already recipients of the organisation's one-to-one counselling scheme (11). As previously expressed, African female migrants in the UK often have issues within the immigration system, in finding employment and being separated from their familial networks. In response to the establishment of the organisation's mixed ethnic women's support group in Edinburgh, African female service users 'felt their needs were a bit different to Scottish women living with HIV/AIDS' (11). Indeed, some African female service users felt that in terms of their personal and ethnic backgrounds, there was too much of a difference to Scottish female service users to share complete peer understanding (11). The establishment of their own support network was viewed as the appropriate solution (11). Such initiatives by PLWHA who are recipients of service provision have been advocated by commentators. For example, Takura and Power (2002) highlight that 'African migrant women living with HIV must be involved from the start in determining appropriate support and services and peer experiences are a vital part of this'.

The Waverley Care African women's support group in Edinburgh uses both a top-down and bottom-up approach in the running of their meetings. The group facilitator stated that her role is to manage the group meetings by having the responsibility 'to contain' the group and 'keep it safe for everybody' (11). In terms of discussion, this is primarily led by the service users, although the facilitator often provides topics that the women can 'explore' (11). Gender-sensitive topics, for example, women's sexual health, sexual practices, forming relationships with men and motherhood are often discussed (11). Other common topics are the socio-economic issues that the women often have in relation to unemployment and housing as a consequence of their immigration status (11).

The use of both a top-down and bottom-up approach is considered the most beneficial framework for running the group meetings because the group facilitator argues that for the women, 'the agenda is theirs (and) not mine' (11). In primarily leading the discussions, the women are able to set the agenda and discuss the issues they feel are most important in their lives. By setting, to a large extent, their own focus with guidance from the facilitator, the women are able to receive the most constructive support possible from one another (11).

### **3.2.2. Waverley Care African women's support group: Glasgow**

An increasing number of service users from the African population in Glasgow came to Waverley Care after the city became a dispersal centre (10). Similarly to Edinburgh, Waverley Care in Glasgow provides a one-to-one support programme for both African male and female service users. However, after it became evident that the issues discussed by the women in these counselling sessions were commonly experienced by the African female service users, Waverley Care formed the African women's support group in Glasgow in order for these women to come together in a peer setting and discuss the problems that they collectively shared (10). For example, social isolation, which, as previously established, is a notable problem for African women living with HIV/AIDS in the UK, was understood to be an existing issue for the majority of African female service users (10). Therefore, among other things, the support group was established to provide the women with the opportunity to interconnect and socialise with others (10).

Unlike the African women's support group in Edinburgh, the support group in Glasgow predominantly uses a top-down approach to manage its meetings. The support group meetings in Glasgow are managed by two facilitators, one of whom is primarily involved in discussion and the other who observes and keeps control of the group dynamic (10).<sup>32</sup> The facilitators provide discussion topics for the women, especially in relation to the management of their physical health, including weight management, medical treatments that are available and the side effects of the medication (10). Like the Edinburgh group, issues such as sexual practices, relationships and motherhood are proposed and discussed (10). Hence, the group facilitators' role is to ensure that the women receive and leave the group meeting with constructive information that can help them manage the physical and emotional effects of their seropositivity.

With regard to structure, the group meetings are managed through the facilitators but there is group participation in the discussion (10). The form of the facilitators' involvement is deemed most suitable because it was presumed that if the service users were placed in charge of leading the discussions, the group may become solely an opportunity to socialise (10). It is significant that this is avoided because the facilitators argue that service users are obligated to know certain information, for example, concerning HIV prevention and the

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<sup>32</sup> I only interviewed one of the two facilitators in order to create an equal balance within the overall number of facilitators interviewed for the research.

biological disposition of HIV/AIDS. As Mildred Zimunya comments, 'You might know how it feels to be told you are HIV positive, to be stigmatised but you might not have information about the disease' (10).

Nevertheless, because 'there has to be that balance between providing information and sharing their experiences' (10), the women who 'have a lot to contribute', do benefit from the group by participating in the meeting discussions, which provides them with the opportunity to share their experiences and opinions in relation to the proposed topics (10). Therefore,

the involvement of the women in discussing their needs and experiences and hence participating in the group dynamic can be perceived as their 'right' to 'have a voice' and play a role in a programme that is meant to support and benefit their management of HIV/AIDS (Tallis, 2002:34; Cornwall and Welbourn, 2002).

### **3.3. Terrence Higgins Trust's African women's support group**

Terrence Higgins Trust created its African women's support group as part of an existing programme that provides support groups for PLWHA (Terrence Higgins Trust, 2011b). Similarly to Waverley Care, THT has a mixed ethnic women's support group available but established the African women's support group based on the rationale that African female service users need an intervention that is specific to their ethnic and cultural backgrounds (6). However, the THT group differs from the other two support groups in that it was created particularly for African women who have experienced sexual violence (Terrence Higgins Trust, 2011b).

Similarly to the Waverley Care group in Glasgow, the THT group meetings are principally operated using a top-down approach as the meetings are solely led by the facilitator (6). This approach is used by the THT group as a previous trial using an exclusively bottom-up approach was deemed ineffective for running the group meetings. Hosanna Bankhead (6) argues that the women in this group are mentally vulnerable, as many have come from backgrounds of conflict and instability in their home countries. Although seeking asylum has been determined as a major pull factor for Africans who decide to migrate to the UK in search of safety and protection, it is nevertheless characteristically a traumatic process as 'their displacement can result in loss of family, friends, land and other possessions, disruption of education, employment and erosion of community structures and traditions'

(Thomas *et al*, 2010:101). Therefore, the women are perceived to be too emotionally vulnerable to run the group suitably and to a level at which they could offer beneficial support to one another (6).

Therefore, the facilitator presents topics of a similar nature to those discussed in the other two groups and leads the meetings to ensure that the women receive the most constructive support from her and from each other (6). However, participation is extensively open within the THT support group as the service users are able to ask questions relating to the presented topics and also to present any individual concerns to the group (6).

### **3.4. Conclusion**

As Prost *et al* (2008:191) argue, 'involving community-based organisations (...) remains the key to designing effective interventions with Africans living with HIV'. The establishment of support groups for African women living with HIV/AIDS by Waverley Care and Terrence Higgins Trust represents an important breakthrough within service provision for the African population in Edinburgh and Glasgow, especially as they are often considered to be marginalised within wider society (Souley *et al*, 2011). The support groups discussed were commonly set up to meet the specific needs of African female service users and provide a safe, communal environment where they can share their experiences and concerns.

Although none of the groups are primarily led by the service users, they are given a fair opportunity to share their concerns and experiences, as well as to benefit from receiving information that can help them improve their physical health and manage the difficulties that HIV/AIDS can bring to their lives (Tallis, 2002; Liamputtong *et al*, 2009). The involvement of the facilitators in the groups varies in terms of managing the structure of the meetings. However, their presence can be viewed as essential within the operation of the group meetings because of their information provision to service users and their role in ensuring that the group environment is kept safe and open for discussion.

Having shown how these African women's support groups operate within a developmental framework to assist female service users, it is important to now evaluate the arrangement of the support groups as both gender and ethno-specific interventions. From this evaluation, it can then be determined to what extent the specificity of the groups benefits the women's experiences within them and their management of HIV/AIDS.

## **4. Benefits and Drawbacks of forming gender and ethno-specific support groups for African women living with HIV/AIDS**

### **4.1. Introduction**

With regard to support groups for women living with HIV/AIDS, Visser *et al* (2005:342) argue that 'more extensive research is needed to assess the effectiveness of such an intervention in providing support to women'. In trying to meet this research gap, it is important to consider the benefits and drawbacks for service users involved in these African women's support groups. This analysis is done from the perspective of the groups' ethno and gender-specific arrangement which it is significant to consider, as it allows one to determine how their specificity affects how the women experience their support groups and manage HIV/AIDS in their lives.

### **4.2. Advantages and Disadvantages: The use of a gender-specific approach when forming support groups for African women living with HIV/AIDS**

The African women's support groups established by Waverley Care and THT can be described as gender-specific interventions that aim particularly to help women living with HIV/AIDS (6). This can be considered a breakthrough in the context of the advocacy that 'specific, gender-sensitive support and counselling must be made available for women testing HIV positive' (PozFem, 2008:5). However, to what extent has the use of a gender-specific approach to the formation of these support groups benefited the women in terms not only of their experience within their groups, but also of meeting their needs and helping their management of HIV/AIDS? Before this question is addressed, it is important to readdress in greater depth the social and cultural expectations of women within the African cultural context and how these affect their relations with men, as these are a determining factor in the rationale of using a gender-specific approach in the formation of the African women's support groups.

HIV/AIDS has become a global epidemic partly because its transmission is often interlinked with socio-cultural issues (Healthlink, 2007). This has especially been the case in many African societies where a system of patriarchy dominates and women are expected to play a submissive role to men with regard to sexual practice in order to serve their needs or to produce a male heir, to ensure the continuation of patriarchal rule (Tamale, 2009). Moreover,

within this social context, 'male identity is very much linked to sexual performance' and men often have several sexual partners at once in an attempt to prove their authority and masculinity (UNFPA, 2004b). Women, as previously expressed, are also often not in the position to act upon their right to practice safe sex (Prost, 2005).

Such social expectations and cultural beliefs in relation to men and women continue to form the mind-set of many African women even when they migrate to the UK (6). Therefore, in trying to form interventions for African women living with HIV/AIDS in the local community, this has to be taken into account (6). To this end, the use of a gender-specific format was deemed appropriate in forming the support groups because it was supposed that if men were present within the groups, they could possibly dominate the group dynamic and the women would not then feel free to contribute to discussion, leading to them becoming disempowered in an echo of social conventions (6).

Therefore, the formation of all-women's groups was considered beneficial in order for the women to feel comfortable and allow them to be open in discussing their issues. The rationale behind the gender-specific format was praised by some of the service users. One woman commented 'in the group, you can discuss each other's experiences and learn from others, we are like sisters' (12). Another woman felt it was an advantage not to be in a group with men as she remarked 'we support each other and if you have a doubt, you can talk to a lady and not a man' (13). Marion Chatterley argues that from her experience as group facilitator, the women in her group are not likely to join an African mixed gender group mainly because of their attitude that African men treat women in a discriminatory manner (11).

In addition, as previously established, sexual practice, disclosure of status to and forming relationships with men, and having children are gender-sensitive topics that are often discussed within the African women's support groups. As Esplen (2007:14) argues, 'for many women, a positive HIV diagnosis leads to changes in the way they experience their sexuality'. The gender-specific format of the support groups has been argued to produce the most suitable environment for the women to discuss such issues because women are often uncomfortable discussing issues regarding sexual health (Shah *et al* 1999) and practice amongst men (6)(11).

What importance does the discussion of these particular issues have for women in their management of HIV/AIDS? Firstly, due to service users' experiences of gender relations in

their home countries where men tend to be in control of women's sexuality and fertility as a way to prove their 'superiority' (Tamale, 2009), the women often have difficulty recognising their sexual and reproductive health and rights and convincing their partners to use condoms (6). One of the service users, for example, stated that she did not have the confidence to negotiate safe sex with men and did not want to engage in any sexual activity 'to be on the safe side' in case she indirectly disclosed her seropositivity, which could lead to a stigmatised reaction (14). Hosanna Bankhead (6) argues that one of the benefits for the women being amongst female peers in their support group is that they are able to become empowered together to take control of their sexual and reproductive health and rights and negotiate safe condom use which enables the women to become 'spokespersons for themselves' as well as prevent future HIV transmission.

Secondly, having children is both a difficult and sensitive issue for the women as for some of the service users diagnosis of HIV was made during antenatal care (10). 'For most African women, motherhood is a major source of identity and legitimacy' (Doyal and Anderson, 2006:97) and 'to have a child is to fulfil a norm for women in the African context' (6). However, many of the service users who want to have children have experienced difficulty finding partners because of their seropositivity (10). In addition, women who want to have children but are HIV positive are often considered to be insensitive and tactless because of the risk of transmission of the virus to the baby (Esplen, 2007). However, through the support groups, the women discuss ways they can have children, prevent mother to child HIV transmission and are reminded that motherhood is a 'right' for all women and should not be restricted because they are HIV positive (6)(10).

Although, the all-women's groups were established to allow female service users to benefit in terms of feeling unrestricted to discuss gender-sensitive issues without the presence of men, the use of the gender-specific approach in forming women's support groups for African women living with HIV/AIDS has been argued to have certain drawbacks. Liz Marr from Waverley Care argues that the use of a gender-specific approach in forming these all-women's support groups can be disadvantageous for the female service users as it encourages them to focus on these gender-sensitive issues which can be restricting in terms of group discussion (15). Furthermore, having discussion solely with women can also prevent the broadening of perspectives in the management of HIV/AIDS (15).

Coincidentally, although the majority of the interviewed service users felt there was no disadvantage in being in a support group with only women, several of them expressed their openness to being in a support group with men. As one woman stated, 'we all want to live, that is the main thing so I am not bothered' (16) and another commented that she felt that 'men are supportive' and 'it would make no difference if men were present' within their support group (17). Another woman who was a member of both Waverley Care's African mixed gender support group and African women's support group in Glasgow, commented that from her experience in the mixed group, that 'everyone is just one and supportive' (12); indicating that their shared seropositivity was adequate to form a peer understanding. Similarly, Marion Chatterley argues that the African female service users could also benefit from being in an African mixed gender group as they would have the 'empowerment' opportunity to challenge social conventions regarding the sexual behaviour and practice of African men (11).

From her experience of running an African mixed gender group in Glasgow, Mildred Zimunya agrees arguing that an advantage of the male presence is that it can help women share their worries over male sexual behaviour, as well as to hear men's opinions in relation to their sexual health concerns (10). This is particularly important for African women as outside the support group, there are very few opportunities for them to have upfront discussion about sexual health and practices as they often do not discuss these with their male partners (10). Therefore, if African male service users are present in support groups with the women, it can provide the women with a platform to talk about these issues without affecting their personal relationships outside the support group (10). Consequently, it is evident that when establishing gender-based HIV/AIDS programmes for women, men need to be taken into consideration. By working with men 'to change norms related to fatherhood, sexual responsibility, decision-making and violence', HIV/AIDS interventions and programmes are able to challenge detrimental gender categorisations and norms (WHO, 2011).

#### **4.3. Advantages and Disadvantages: The use of an ethno-specific approach when forming support groups for African women living with HIV/AIDS**

As established, African migrants constitute a significant proportion of the population living with HIV/AIDS in the UK. In taking this into account, there has been pressure for HIV

services in the UK to provide more culturally appropriate and ethno-specific interventions for the African migrant population (Ssanyu-Sseruma, Personal Correspondence, WAND, 2005, Burns *et al*, 2007; Fakoya *et al*, 2008). Mildred Zimunya (10) argues that the rationale behind this is based on the perception that to serve a people 'you have to understand them first and their needs'. In addition, 'there are a diverse range of factors including length of time in the developed world, diverse language capabilities, and community held values, beliefs and practices from one's country of origin, that need to be considered when developing strategic responses to HIV/AIDS' for the African migrant population in the UK (AB-DGN, 2010:4).

Within this context, the African women's support groups could be fairly described as 'ethnic-orientated' interventions (5) that are also 'formed from a cultural perspective' (2).<sup>33</sup> In the past, several of the African female service users in both Waverley Care and THT, expressed their view that their needs and experiences were different from those of Scottish service users because of their legal status, ethnicity and cultural backgrounds, which provided justification for the creation of their own specific support network. Forming support groups with an ethno-specific format can therefore be perceived as a response to service users' particular circumstances in Scotland as migrants from the African continent to provide them with a space where they can meet and talk to others from the same country or a comparable cultural background (2) (5).

There are advantages for the women in being in an all-African support group. Firstly, 'there is a shared similar culture' amongst the African female service users, although they are of different nationalities, which helps them, feel more comfortable and open within the group environment (6). Research supports the use of cultural approaches in HIV/AIDS programmes, as it encourages greater inclusiveness of PLWHA (Healthlink, 2007). Many of the service users also have shared experiences of being subservient to men based on the cultural expectations of women in their home countries and for some being victims of domestic violence (6). In this context, one service user described the main advantage of being in a support group amongst other African women as being 'we are the same people' (18). Therefore, within the group framework, having a similar socio-cultural background enables the women to provide insightful support to one another in coping with their

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<sup>33</sup> In evaluating the ethno-specificity of the support group arrangement, consideration of service users' cultural backgrounds is necessary as ethnicity can be defined as 'a multi-faceted phenomenon based on physical appearance, subjective identification, cultural and religious affiliation, stereotyping, and social exclusion.' (Berthoud *et al*, 1997 in Bulmer, 2010:111).

seropositivity and sexual relations with men that would not necessarily be possible within a mixed ethnic women's support group (5).

However, Othieno (1998:30) appropriately highlights that 'it is important that anyone working with Africans undertakes to appreciate the diversity of backgrounds that may exist'. Furthermore, while the shared ethnic and cultural background of the female service users has advantages in terms of how the women experience and benefit from their group, the approach can be limiting. Some of the service users, for example, expressed that it would be beneficial to interact with PLWHA from other ethnic groups in order to learn about different cultures and that it was their shared seropositivity that primarily mattered within the group dynamic. As one interviewee stated, 'ethnic differences do not matter, we are all the same' (14).

Another service user who is a member of both the Waverley Care African women's support group and the mixed ethnic women's support group in Edinburgh stated that in the latter, she finds it beneficial to interact with Scottish service users as she is able to learn more about their cultural background (19). She also felt that it was refreshing to interact with women in the mixed ethnic support group who are bisexual or lesbian because all the women in the African women's support group are heterosexual (11) and are sensitive around homosexuality (19). This is because of the legal restrictions (Day, 2011; Smith *et al*, 2009) and cultural taboo (Othieno, 1998) that exists around homosexuality in many sub-Saharan African regions. The interviewee commented that back in her home country 'if you are a lesbian, it is fourteen years in prison' (19). Othieno (1998:72) elucidates that although 'the Western world promotes the concept of the individual, African societies place greater emphasis on the extended family and the community at large, and procreation tops the agenda'.

#### **4.4. Conclusion**

This chapter aimed to provide an assessment of the benefits and drawbacks of using both a gender and ethno-specific approach in the formation of the African women's support groups; and how these approaches affect women's experiences within their group and the management of HIV/AIDS in their lives.

The rationale behind the gender-specific approach in forming the African women's support groups was strongly associated with cultural practices and social conventions within the

African context. Therefore, it is beneficial for HIV/AIDS programming in relation to women to be developed through a 'cultural lens' (UNFPA, 2004a:2). These support groups were established principally for women in order to provide them with a space without the possibility of male dominance and to allow the open discussion of sensitive issues regarding their sexual health and practice, as well as fertility issues. However, there was some support for the idea that a male presence within the group framework could be beneficial for the women. Some of the service users were open to being in a support group with men as their shared HIV status was perceived to form a dependable link between them. The presence of men could also provide the opportunity for women to challenge the African cultural gender stereotypes with regard to men's sexual practice and behaviour.

On the other hand, these were solely opinions and not preferences as all the women interviewed expressed appreciating being in an all-women's group and considered their female peers as lifelines in coping with HIV/AIDS within their lives. Notwithstanding, an important outcome from this assessment has been the recognition that African women can be open and could also benefit from being amongst men within this type of support network.

Concerning the application of an ethno-specific approach, being in an all-African support group is beneficial for the women as they can meet, socialise and relate to others from their own countries or similar socio-cultural backgrounds. This can help the group dynamic by making it more open and relaxed for the women to talk about their issues and experiences. The premise for the formation of these African women's support groups was that African female service users need a support network in line with their ethnic and cultural backgrounds and that recognises their social realities as migrants in Scotland. However, some service users expressed their openness to being in support groups with women from different ethnicities because they consider their shared seropositivity adequate to form a peer understanding and it could also provide them with the opportunity to be more aware of cultural and social conventions outside the African context.

## **1. Conclusion**

**'When you're HIV positive you cannot do anything but meeting others in the same position, you know you can' (17).**

The main rationale behind this study was to examine the experiences of and issues facing women living with HIV/AIDS within the African migrant population in the UK, particularly in Scotland. To do this, African women's support groups based in Edinburgh and Glasgow were used as case studies to gain an insight into the lives of the women accessing them. These support groups were also used to determine the type of service provision made available to the women and the extent to which their gender, ethnicity and cultural backgrounds have been taken into account in the process. Support groups were appropriate for the case studies on service intervention because although they have been argued to be very beneficial for PLWHA (Visser *et al*, 2005) they have been generally under researched within the UK context.

This is also the case for African women living with HIV/AIDS in the UK, although their experiences provide validation for study. For many African women who migrate to the UK in search of a better life or to be reunited with relatives a life consisting of poverty and discrimination often awaits them. Issues that can arise with their legal status can detrimentally affect their livelihoods as it sanctions their immobility and prevents their access to employment. To become infected with HIV/AIDS whether prior to migration or in the UK forms an additional burden in the lives of these women (2). For many African female migrants living with HIV/AIDS in the UK, managing the emotional and practical difficulties of the disease can be difficult, particularly in relation to stigmatising attitudes and discrimination that they can be subjected to in response to their seropositivity from relatives and friends within their local community and in their homelands, as well as from wider British society. Therefore, for many African women living with HIV/AIDS in the UK, to manage life with the disease can be a difficult process as they frequently have to cope with socio-political barriers as a migrant in a country faraway from where they consider 'home', as well as societal isolation as a consequence of the discrimination they face because of their seropositivity.

However, by joining a HIV/AIDS support group these women are able to 'realise that they are not alone in the lonely world of life with HIV/AIDS' (Liamputtong *et al*, 2009:6). The African women's support groups were created by Waverley Care and Terrence Higgins Trust with the intention not only of ensuring that African female service users no longer try to cope

with HIV/AIDS in isolation but also with the objective of meeting their needs and catering for their daily circumstances. Therefore, the support groups operate their meetings within a developmental framework with a general consensus that the facilitators guide or lead the service users in discussions to ensure that they are provided with the most constructive type of support. However, it is essential that participation from the service users is achieved at some level in the group meetings as it is their entitlement to be involved in programmes formed to help their management of HIV/AIDS.

On the other hand, by determining the specific ethno-centred format of the support groups, certain benefits and drawbacks of this were found for the women's experiences in their group and management of HIV/AIDS. Although the women generally found it favourable to be amongst those of shared ethnicity and a similar socio-cultural background, some service users were open to being in a peer environment with women from different ethnic backgrounds and declared that their shared seropositivity was enough to form a connection.

As this study was gender-based in nature, it was also important to consider this same analysis within the support group's gender-specific format. Fittingly, Villela and Barber-Madden's (2009:697) definition of gender as 'an idea that embraces individuals and socially organised collectives at one and the same time' can be considered appropriate in describing what the support groups have been able to provide for the women who took part in this study. For these women, their support group is considered more than a support network; it is where they can become empowered as individuals and join together as a sisterhood. As Liamputtong *et al* (2009:7) reiterate, 'joining support groups creates collective power for all women, and this collective power allows the women to defend their conditions and deal with their self in a more positive light'.

Furthermore, by being within a shared gender environment, these women feel more open to talk about sensitive issues regarding their sexual and reproductive health. In terms of future research, women living with HIV/AIDS have gender-sensitive issues that justify their own research investigation. There should consequently be a review of support groups and other service provision that takes this into account for African female migrants living with HIV/AIDS in other parts of the UK.

Villela and Barber-Madden (2009:698) argue that 'the category of gender has proved quite valuable in academic work and in interventions based on (...) challenging certain norms,

especially those concerning partner submission'. Accordingly, the involvement of men in gender-based programmes for women, such as the African women's support groups, is also considered important. For example, through peer support in the groups women can become empowered to reject imbalanced socio-cultural conventions regarding to their sexual expectations with men. There is some support for African support groups consisting of men and women as another way for women to challenge their male counterparts about their sexual behaviour and practice. However, within the context of this study, it is important to remember that these women have chosen to be in these support groups and although some were open to having male peers in the group fold, this was only a viewpoint and not a predilection.

By evaluating the African women's support groups, a perception of women's experiences with HIV/AIDS was achieved. However, this also represents the study's main limitation, as 'the main disadvantage in using community based support groups is that the participants may not be representative of HIV positive Africans who choose not to attend these groups' (Erwin and Peters, 1999:1524). Nevertheless, gaining insight into these women's experiences and their use of support groups as a strategy to manage HIV/AIDS within their lives hopefully contributes to research on the experiences of and service provision available for African women living with HIV/AIDS in the UK.

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## Appendix

### Interview List

- (1) Roy Kilpatrick, Chief Executive, HIV Scotland and Andrew Gardiner, Senior Development Officer, HIV Scotland (9/6/11).
- (2) Hosanna Bankhead, Group Facilitator, Terrence Higgins Trust, Glasgow (30/6/11).
- (3) Eunice Sinyemu, Deputy CEO, African Health Policy Network (8/6/11).
- (4) Dr Dina Sidhva, Teaching Fellow, Social work, School of Social and Political Science, University of Edinburgh (4/7/11).
- (5) Mildred Zimunya, Group Facilitator, Waverley Care, Glasgow (15/7/11).
- (6) Hosanna Bankhead, Group Facilitator, Terrence Higgins Trust, Glasgow (14/7/11).
- (7) Marjorie Clark, Co-Ordinator of the Church of Scotland's HIV Programme, Church of Scotland, Edinburgh (5/5/11).
- (8) Marion Chatterley, Group Facilitator, Waverley Care, Edinburgh (18/5/11).
- (9) Dr Afe Adogame, Senior Lecturer in World Christianity, School of Divinity, University of Edinburgh (25/5/11).
- (10) Mildred Zimunya, Group Facilitator, Waverley Care, Glasgow (6/6/11).
- (11) Marion Chatterley, Group Facilitator, Waverley Care, Edinburgh (17/6/11).
- (12) Service user, Zimbabwean, 57 years old, Waverley Care, Glasgow (6/7/11).
- (13) Service user, Gambian, 38 years old, Waverley Care, Glasgow (8/7/11).
- (14) Service user, Nigerian, N/A, Terrence Higgins Trust, Glasgow (30/6/11).
- (15) Liz Marr, Care Team Manager, Milestone respite centre, Waverley Care, Edinburgh (16/6/11).
- (16) Service user, Zimbabwean, 38 years old, Terrence Higgins Trust, Glasgow (30/6/11).
- (17) Service user, Zimbabwean, 45 years old, Terrence Higgins Trust, Glasgow (30/6/11).
- (18) Service user, Zimbabwean, N/A, Terrence Higgins Trust, Glasgow (30/6/11).
- (19) Service user, Malawian, 49 years old, Waverley Care, Edinburgh (16/6/11).