

A critical appraisal of a creative arts support group for women living with HIV

A Work-Based Placement Project at Waverley Care

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EXECUTIVE SUMMARY

Background

HIV-related stigma has been found to lead to social isolation (Lichtenstein et al., 2002), which can instigate barriers to health service access (Heijnders and van der Meij, 2007) and further contribute to poor mental and physical health (Groves et al, 2010; Emlet, 2006). What is less clear is the role that support groups play in assisting women living with HIV to cope with stigma and reduce their social isolation. The purpose of this research was to critically appraise the strengths and limitations of Isis, the creative arts-based weekly support group held at Waverley Care, and how it has been transformational for women living with HIV to overcome social isolation.

Findings: The Key Messages

This qualitative feminist constructivist research project, that entailed participant observation, narrative interviews and a focus-group, viewed the female participants as experts because of their lived experiences with HIV and Isis. The findings revealed that Isis provided women with a nonjudgmental environment, confidence building and self-worth, creative arts as therapy, confidentiality, financial support, longevity and flexibility of attendance, social support, advocacy, and engagement outside of Isis. Participation in the art-based programme with these components was found to be transformational in several ways, especially in reducing the women's social isolation and helping them deal with the stigma of HIV. While the women's assessment of Isis was extremely positive, four limitations were identified that included finding ways to overcome stigma against women who have contracted HIV through drug use, raising additional funding, increasing social spaces to enhance interpersonal connections, and making the space wheelchair accessible.

Conclusions and Recommendations

Isis can serve as an exemplary case study for replication and continued funding. It is recommended that Waverley Care explore ways of overcoming the limitations and communicate its structure, method of operating, and the benefits of participating in Isis to increase awareness and attract additional participants. Future research is necessary to determine if the strengths of the programme are beneficial in other contexts and for other sub-groups living with HIV. This will serve as an evidence base for other health organisations and policy makers to devote greater resources and policies to similar community-based support groups.

TABLE OF CONTENTS

Chapter 1: Introduction.....	6
Chapter 2: Literature Review.....	9

2.1: Stigma and Social Isolation.....	9
2.2: The Role of Creative Arts Support Group in Reducing Social Isolation.....	12
Chapter 3: Qualitative Methodology.....	14
3.1: Feminist Constructivism.....	14
3.2: Participant Observations.....	14
3.3: Narrative Interviews.....	14
3.4: Focus Group.....	15
3.5: Ethics Summary.....	16
3.6: Data Analysis.....	17
3.7: Limitations.....	17
Chapter 4: Findings & Discussion.....	18
4.1: Background on Isis.....	18
4.2: Background on Study Participants.....	19
4.3: Stigma & Social Isolation.....	19
4.3.1: Fear of Disclosure.....	20
4.3.2: Low Self-esteem.....	21
4.4: Isis: Key Strengths of the Weekly Creative Arts-Based Support Group.....	21
4.4.1: Nonjudgmental Environment.....	22
4.4.2: Confidence Building & Self-worth.....	22
4.4.3: Creative Arts as Therapy.....	23
4.4.4: Confidentiality.....	24
4.4.5: Financial Support.....	24
4.4.6: Attendance: Longevity & Flexibility.....	25
4.4.7: Social Support.....	26
4.4.8: Advocacy.....	28
4.4.9: Engagement Outside of Isis.....	29
4.5 Key Limitations of the Programme.....	30
4.5.1: Overcoming Stigma.....	31
4.5.2: Financial Barriers.....	32
4.5.3: Location.....	32
4.5.4: Wheelchair Accessibility.....	32

Chapter 5: Conclusion & Recommendations.....34
References.....37
Appendix I: Demographic Characteristics.....42
Appendix II: Consent Form.....43

CHAPTER 1: INTRODUCTION

According to the World Health Organization (WHO, 2014a), in 2014 there were 36.9 million people living with human immunodeficiency virus (HIV) and 1.2 million who died from acquired immune deficiency syndrome (AIDS) related illnesses worldwide. In 2015, the National Health Service (NHS) Scotland reported that, “the cumulative total of known HIV-positive individuals ever reported in Scotland is 8092, of whom 5900 (73%) are male and 2192 (27%) are female, and at least 1938 (24%) are known to have died” (p.184). NHS Scotland (2015) estimates that 4967 individuals are living with HIV in Scotland today. The number of women living with HIV in the UK (1,530) is rising faster than the number of men (1,050), according to Public Health England (2013). Although the cases of HIV-acquired by heterosexual contact has declined by more than a half abroad, in the UK, the second largest group of newly diagnosed HIV cases are individuals who acquire HIV through heterosexual contact (Public Health England, 2013). These statistics reveal that the HIV crisis is not only prevalent in the UK, but the rising infection rate amongst women is increasingly becoming a key public health concern.

The Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (OHCHR and UNAIDS, 2006) made the link between HIV and human rights when they wrote that:

The impact of HIV highlighted the inequities and vulnerabilities leading to increased rates of infection among women, children, the poor and marginalized groups, and thereby contributed to a renewed focus on economic, social and cultural rights (p.6).

Similarly, led by the Scottish Human Rights Commission, Scotland's National Action Plan for Human Rights (SNAP, 2015) advocates for integrated health and social policies and practice that utilise a human rights based approach. The principles, first drafted in the 1948 Universal Declaration of Human Rights, stated that: “respect for the fundamental dignity of each and every person lies at the heart of human rights, as do the principles of equality and individual autonomy” (SNAP, 2015, p.2).

According to the WHO (2014b), there is growing evidence that “health policies and programmes are more effective and have a more positive impact on health outcomes when affected populations take part in their development” (p.100). Similarly, HIV Scotland (2013), the national HIV policy charity, argued that in order to meet policy objectives, the role of the

voluntary sector must be recognised and the people accessing services must be involved in their design and delivery. Thus, the concept of community empowerment, which is defined as “a collective process that enables key populations to address the structural constraints to health, human rights and well-being; make social, economic and behavioural changes; and improve access to health services” (WHO, 2014, p.100b), is thought to be fundamental to HIV programmes and initiatives. For individuals living with HIV, community empowerment may be realised by asserting their human right to live a life of dignity and respect (Boneh and Jaganath, 2011). This includes the right to health whereby individuals can access affordable HIV treatment, care and support (OHCHR and UNAIDS, 2006).

Yet HIV-related stigma and discrimination is prevalent and is linked to ignorance and misconceptions such as not knowing that HIV is transmitted through sex without a condom or that the disease is no longer fatal (National AIDS Trust, 2010). Over two-thirds of people in a nationwide survey on public attitudes agreed that a high level of stigma surrounding HIV exists in the UK, and one-third of people living with HIV reported experiencing discrimination based on their HIV status (National AIDS Trust, 2010). In a study by Lichtenstein et al. (2002) examining chronic sorrow amongst HIV-positive patients, stigma was found to lead to social isolation. The effects were particularly stark in the case of African American women with children who were more stigmatised and isolated than gay men because others perceived them to be “associated with dirty sex, contagion, and moral threat” (Lichtenstein et al., 2002, p.27). Stigma and social isolation also instigated barriers to health service access and treatment adherence (Heijnders and van der Meij, 2007) and further contributed to poor mental and physical health (Groves et al., 2010; Emler, 2006). What is less clear is the role that support groups may play in assisting women suffering from HIV to cope with stigma and reduce their social isolation. This is the gap in the literature that this study begins to address.

The WHO (2003) highlighted how both sex and gender are linked to individual risk and vulnerability to HIV infection and the ability to access treatment. Sex is defined as a biological distinction between women and men whereas gender is “a social construct that differentiates the power, roles, responsibilities, and obligations of women from that of men in society” (WHO, 2003, p.9). Gender inequality has an economic and social impact on an individual’s ability to cope with illness, act as a caregiver, and survive the death of a loved one (WHO, 2003). Sherr et al. (2012) compared the mental health of HIV positive

heterosexual men and women who attended UK HIV clinics and found the women were more likely than the men to suffer from high psychological and global symptom distress.

In the early 1980s, Edinburgh was considered to be the AIDS capital of Europe with surveys reporting that over 65% of heroin addicts were HIV-positive (Gossop, 2004). Waverley Care (2015), a charitable organization that adopts a support group approach, was established in 1989 as a response to the staggering HIV epidemic in Edinburgh through prevention, education, testing, and support. In recent years, Waverley Care (2014) has aligned with the national Scottish health goals of: “(1) fewer new infections of [HIV and Hepatitis C], (2) a reduction of health inequalities, (3) people affected lead longer, healthier lives, and (4) a society whereby attitudes towards those affected by HIV or Hepatitis C are non-stigmatising and supportive” (p.2). Isis is the creative arts-based weekly support group for women living with HIV, one of many integrated services provided by Waverley Care for people affected with HIV or Hepatitis C across Scotland. According to Boneh and Jaganath (2011), the creative arts are an effective avenue for confronting HIV/AIDS as it places “a greater emphasis on the creative process, engaging people living with HIV/AIDS, and focusing on contextual barriers to prevention and care” (p.455).

In 2015, Waverley Care expressed interest in having qualitative research done to obtain input from Isis participants to better understand the role of the support group in the lives of women living with the stigma of HIV. The purpose that Waverley Care wanted addressed through this study was to critically appraise the strengths and limitations of the creative arts-based weekly support group and how it has been transformational for women living with HIV to overcome social isolation.

CHAPTER 2: LITERATURE REVIEW

In the first part of this literature review, research on stigma is discussed because women would not experience the degree of social isolation they do without the pervasive HIV-related stigma that exists in society (Hackl et al., 1997; Judgeo and Moalusi, 2004). While the elimination of stigma requires structural level strategies, such as public HIV education and policy to address income and other inequalities faced by people with HIV, the weekly support group at Waverley Care seeks to increase health and wellbeing and reduce social isolation of women with HIV in the community. As a result, the second part of this section provides an overview of research related to support groups and art-based therapy.

2.1 Stigma and Social Isolation

Goffman (1963) defined stigma as: “The phenomenon whereby an individual with an attribute is deeply discredited by his/her society and is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity” (p.3). He argued that stigma is the act of discrediting someone into a less desirable category and the resulting forms of discrimination greatly reduce one’s life chances. Goffman (1963) theorized how stigma destroys social identity and sinks the targeted individual into social isolation because: “It has the effect of cutting him/her off from society and from himself/herself so that he/she stands a discredited person facing an unaccepting world” (p.19).

Many HIV-positive women experience stigma because the disease is associated with stigmatised groups such as gay men, immigrants, injecting drug users, and commercial sex workers. Research has shown how this can result in rejection from family, friends, employers, colleagues, fellow church members and medical professionals (Carr and Gramling, 2007; Sandelowski, et al., 2004; Judgeo and Moalusi, 2004). A study by Heijnders and van der Meij (2007) explored the impact of stigma on access and uptake of public health interventions and found that it can lead to a “delay in presentation to health services, prolonged risk of transmission, poor treatment adherence and increased risk of disability and drug resistance” (p.353). Once diagnosed with HIV/AIDS, women’s psychosocial fears often eclipse those relating to physiological damage or death from the disease (Carr and Gramling, 2007). Gender is an important consideration because in their study, female participants self-identified as mothers, wives, or with their respective careers before diagnosis. However, after

diagnosis, women perceived themselves as exclusively being women living with HIV/AIDS and blamed themselves for contracting the disease (Carr and Gramling, 2007).

Carr and Gramling (2007) also examined “the double-edged sword of disclosure” and how revealing one’s HIV status can lead to moral judgments by loved ones, while maintaining secrecy resulted in further “social isolation, depression, anxiety, and alienation” (p.37). Research by Gielen et al. (2000) found that women living with HIV who had a history of physical or sexual violence experienced greater adversity after HIV status disclosure. Hackl et al. (1997) examined the dual obstacles for women living with HIV as both patient and family caregiver as many women concealed their HIV status and focused on their families’ needs instead of their own. Studies have also shown that isolating becomes a coping strategy for women because fears of stigma often prevent them from seeking support (Hackl et al., 1997; Judgeo and Moalusi, 2004).

The mode of HIV/AIDS transmission has been found in some studies to impact the level of stigma experienced (Crandall, 1991; Sandelowski, et al., 2004). Sandelowski et al. (2004) found that although the majority of HIV-positive women in their study were infected through monogamous and heterosexual relationships, the women were accused of contracting the disease through intravenous drug use, promiscuity, or prostitution. These authors argued that, after multiple exposures to stigma, women may internalise preconceived stereotypes about HIV transmission making them even more susceptible to stereotypes and stigmatised labelling. In addition to gender, race, social class, HIV exposure risk category and other factors can intersect to produce complex layers of stigmatisation (Sandelowski et al., 2004). For instance, women who injected drugs intravenously often felt greater stigma for being drug users than being HIV-positive. While being HIV-positive can be very disempowering, it can become a gateway for accessing health services that have helped some women to recover from drug addiction and reclaim their health and relationships (Sandelowski et al., 2004).

There is some research on the links between stigma, social isolation and poor physical and mental health. For example, Grov et al. (2010) found that depression in older adults was significantly associated with HIV-related stigma, loneliness, diminishing cognitive functioning and decreasing energy levels. The findings suggested that initiatives focused on stigma and loneliness reduction need to “assert more aggressive and innovative efforts to resolve both psychosocial and physical health issues that characterise the greying of the

AIDS epidemic in the USA” (Groves et al., 2010, p.630). In another study, Emlert (2006) compared the social networks of older and younger adults living with HIV/AIDS in the Pacific Northwest and found that along with age, gender, heterosexual transmission, and ethnic background impact access to social supports that reduce isolation. The study advocated for health care professionals and social workers to “personally fight against ageist, homophobic, or HIV-stigmatising beliefs in themselves, their colleagues, and the general public that could reinforce myths about aging, sexuality, and HIV/AIDS” (Emlert, 2006, p.307).

Research has also been done on public health policy recommendations and community interventions directed towards the promotion of life-enhancing environments and the alleviation of suffering for those living with HIV/AIDS (Duffy, 2005; Heijnders and van der Meij, 2007; Parker and Aggleton, 2003; de Souza, 2010). Parker and Aggleton (2003) emphasised the importance of examining the structural dimensions of HIV and AIDS-related stigma and discrimination that “feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality” (p.13). In order to evoke social change, the research called for interventions that harness the resistance to power and domination by individuals and communities affected by HIV/AIDS. de Souza (2010) called for future research to “explore stigmatization as a social process that unfolds along lines of power and powerlessness as well as the agency that women demonstrate in the midst of oppression” (p.251).

There has been some research that has evaluated stigma-reduction strategies. A review by Heijnders and van der Meij (2007) identified stigma-reduction strategies on intrapersonal, interpersonal, organisational/institutional, community and governmental/structural levels. At the intrapersonal level, interventions to combat internalised stigma are focused on “changing characteristics of the individual such as knowledge, attitudes, behaviour, self-concept, improving self-esteem, coping skills, empowerment, and economic support” (Heijnders and van der Meij, 2007, p.355). Interpersonal interventions target health promoting environments and focus on the patients and family, the workplace, and friendship networks. The community level strategies support education, contact, advocacy and protest movements to demystify stereotypes that stigma is based upon. Heijnders and van der Meij’s (2007) argued that effective intervention strategies should begin with a patient-centered model aimed

at the intrapersonal level to inspire patients to actively develop projects that extend to the other intervention levels.

2.2 The Role of Creative Arts Support Groups in Reducing Social Isolation

Research suggests that social support networks are a low-cost and beneficial strategy for improving the psychosocial and physical health of women living with HIV (Simoni & Cooperman, 2010; Lennon-Dearing, 2008; Gielen et al., 2001). Lennon-Dearing (2008) found that the physical and emotional health benefits of attendance in women-only HIV support groups included: “an increase in medication compliance, decreased risk behavior for re-exposure to HIV, reduced feelings of shame, and a network of friends to socialise with” (p.27). Gielen et al. (2001) studied the relationship between psychosocial factors and health related quality of life among women living with HIV. The study reported a positive correlation between women with larger social support networks and increased mental health and quality of life. Women were also found to experience a greater overall quality of life and enhanced physical and mental health when they undertook a greater number of self-care behaviours such as a “healthy diet and vitamins, adequate sleep and exercise, and stress management” (Gielen et al., 2001, p.315). The findings suggest that initiatives focused on social support and self-care behavior promotion can improve the health of HIV-positive women. However, women with a history of sexual and physical violence face significant barriers to developing social support networks and self-enhancing behaviours after disclosing their status because they are more likely to lose their jobs, homes, and family. In addition, further support may be necessary for more isolated women, such as older women, women with disabilities, and women who have been hospitalised for HIV-related illnesses (Gielen et al., 2001).

Early research by Aldridge (1993) proposed creative art therapies focused on the restoration of hope as being integral to HIV/AIDS treatment. He suggested that the creative arts hold value outside of the normative biomedical model because:

Not only do they offer an existential form of therapy that accepts patients as they are and affords them an opportunity to define themselves as they wish to be, they are primarily concerned with aesthetic issues of form and existential notions of potential rather than concepts of pathology (p.285).

Aldridge (1993) described art therapy as an antidote to social isolation because it allows the patient to collaborate creatively while being devoid of the shackles of stigma. He theorised

that the arts provide a venue for patients to explore a newfound creative identity that can emerge apart from their disease. Creative art therapies can be a powerful medium for changing an HIV-positive individual's life, although Aldridge (1993) acknowledged this is difficult to measure because:

The elusive life qualities inherent in creative activities - joy, release, satisfaction, simply being - are not readily susceptible to rating scales. We can, however, hear them when they are played, see them when they are painted or danced, and feel them when they are expressed dramaturgically (p. 295).

A study by Baumgartner (2002) found that social interaction was transformational for research participants who changed from "frightened, stigmatised individuals to empowered, confident people" (p.54). Through group participation with other HIV-positive members, the women learnt that they were not the only ones living with the disease, that they could live healthy and full lives, and that together, they could breakdown societal barriers to stigma and HIV/AIDS treatment access (Baumgartner, 2002).

CHAPTER 3: QUALITATIVE METHODOLOGY

3.1 Feminist Constructivism

A feminist constructivist approach was utilised in this study and it had also been employed in an earlier evaluation of a Waverley Care project from 2009-2013, known as the Positive Scotland Evaluation (Sidhva, 2013). With feminist constructivism, multiple perspectives are valued instead of seeking pre-specified outcomes and women are viewed as experts “because of their knowledge, understanding, and lived experience” (Sidhva, 2013, p.16). It typically involves qualitative methods whereby “researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them” (Denzin and Lincoln, 2000, p.3). The qualitative methods used in this study included: i) participant observation of the weekly Isis support group, ii) narrative interviews and iii) a focus group with a creative arts project. The unstructured nature of these research methods was intended to facilitate a welcoming environment to provide a space for discussion of issues that were most important to participants (Bauer, 1996).

3.2 Participant Observations

Upon receiving ethical approval to proceed, participant observations involved my active participation in weekly creative art projects that were assisted by facilitators and artists over two months between June and July, 2015. The goals of the participant observations were to build trust amongst Isis group members and to better understand how the support group operated (Janesick, 2000). Weekly field notes were taken that included my reflections on my role as the researcher. The collaborative participation focused on women engaging in dynamic relationships but “there is no pure, objective, detached observation; the effects of the observer’s presence can never be erased” (Denzin and Lincoln, 2000, p.634).

3.3 Narrative Interviews

Narrative interviews, as described by Aranda and Street (2008) and Aldridge (2015), were utilised to explore the role of the weekly Isis support group in the women’s lives, to reflect on its potential transformational aspects, as well as its limitations, and to discover the role of creative arts in a peer-support group setting. Riessman (2004) defined narrative interviews as experiential stories whereby “participants engage in an evolving conversation; narrator and listener/questioner, collaboratively, produce and make meaning of events and experiences that the narrator reports” (p.710). Narrative stories are effective in exploring “practice,

setting, situations, and their resolutions or actions and to show learning from experience” (Loewenson et al., 2014, p.48). During the unstructured narrative interviews, Isis participants were asked if and how Isis had helped them overcome social isolation and what they felt the group’s strengths and limitations were. Their responses were then probed further by asking questions like: ‘What happened then?’ (Bauer, 1996).

Ten members of the weekly support group were invited to participate in sharing personal narratives of their experiences in the creative arts-based support group that best captured their experiences using their own language (Ridge et al., 2007; Anderson et al., 2008). Seven Isis members agreed to participate in the study. I was unable to arrange interviews with three additional women as one was on vacation, the second did not have the time, and the third did not return my telephone message. Before each interview, I asked each woman to fill out basic demographic characteristics (see Appendix 1) and the information was summarised anonymously to prevent any connections made to their interview responses. In addition, I also conducted interviews with two Isis facilitators and one art project facilitator to obtain their perspectives on the role of the support group and how it operates. All interviews were audio-taped and transcribed verbatim.

3.4 Focus Group

A follow-up focus group was held at the end of July to validate themes and discuss key findings. The focus group allowed participants to “explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities” (Kitzinger, 1995, p.299). I audio-recorded a round-table discussion with the women and presented the preliminary themes I had identified. Even though not every woman spoke to every theme in their narrative interviews, they agreed that the themes collectively captured their experiences with stigma and social isolation, the role Isis has played in their lives, along with the strengths and limitations of the programme.

Increasingly, qualitative studies have incorporated creative methods such as music, art, dance, drama, poetry, and photography that foster experiential benefits (Aldridge, 1993). Given the creative nature of the Isis support group, I developed and led a mask decorating project during the focus group. The idea for the mask project was inspired by a quote by an Isis member on the Waverley Care (2015) website that said: “I can take off the face I wear for the outside world and just be myself.” The women decorated masks to symbolise what

participation in the Isis group has meant to their lives and their descriptions of their creative processes were audio-recorded (Ponic and Jategaonkar, 2010). This helped to corroborate findings as well as gain additional insights for this research.

3.5 Ethics Summary

The following is a summary of the Ethical Review for level 2 auditing that received approval from the Research and Research Ethics Committee of the School of Social and Political Studies at the University of Edinburgh in 2015. In terms of potential risks to participants, my research was not likely to induce psychological stress or discomfort or involve physically invasive or harmful procedures. In addition, the women were not asked to disclose information about child abuse or other information that would result in the researcher breaching confidentiality conditions. It was also unlikely that the research findings or participation in the research would adversely affect the participants in any way, nor were there any psychological or physical potential risks to me, the researcher.

During the narrative interviews and the focus group, I did not ask about the participant's behaviours, experiences or health conditions but was specific to their experience with the project. Data collection was conducted at Waverley Care, so in the case of any emotional distress, support and counselling was available. The benefits of this research outweighed the risks because the women are likely to benefit from reinforcing what is working well in the group and identifying improvements that could be made based on the recommendations. While women living with HIV are members of a vulnerable and stigmatised minority in Edinburgh, this research considered them to be experts because of their lived experience with HIV and the Isis support group.

All participants in Isis during May and June, 2015 were invited to participate in the research. Anyone who did not feel comfortable at any time throughout the duration of the research had the option of withdrawing. Written informed consent (see Appendix 2) was obtained by all participants in addition to their free and on going consent. The consent forms were verbalised because some of the participants may have had low literacy levels, although all of them did speak English. All participants were given pseudonyms so they could remain anonymous in the reporting of this research.

3.6 Data Analysis

An exploratory approach to qualitative data analysis was utilised to determine major themes and to structure the research findings. This approach was content driven and involved the following stages: “the researcher carefully reads and rereads the data, looking for key words, trends, themes or ideas in the data that will help outline the analysis, before any analysis takes place” (Guest, et al., 2012, p.9). The major themes and sub-themes identified were i) stigma and social isolation (fear of disclosure and low self-esteem), ii) key strengths of Isis (non-judgmental environment, confidence building and self-worth, creative arts as therapy, confidentiality, financial support, longevity and flexibility of attendance, social support, advocacy, and engagement outside of Isis), and iii) key limitations of Isis (overcoming stigma, financial barriers, location, and wheelchair accessibility).

3.7 Limitations

This study took place over a short duration with a small population size and therefore the findings cannot be generalised to other contexts. Another limitation is that women who are regular attendees may have had more favourable views on the support group than less frequent attendees or those who have stopped participating. Nonetheless, the study does provide Isis participants and Waverley Care with evidence that can be used to reinforce the aspects of the support group that are beneficial to current participants as well as consider the recommendations for improvement.

CHAPTER 4: FINDINGS & DISCUSSION

4.1 Background on Isis

While there is written documentation on Waverley Care and many of its other programs, there is little written material on the rationale, history and structure of Isis. Through discussions with the group facilitators and participants and observations at weekly Isis meetings, the following background information was obtained.

Isis, the weekly support group for women living with HIV, has been running at Waverley Care for nearly 20 years. During this time, due to improvements in treatment, HIV has shifted from being considered to be a terminal disease to a chronic health condition (Waverley, 2015). Isis has two group facilitators who are funded by the NHS, and the arts budget is funded by Edinburgh City Council. The group meets every Tuesday afternoon from 13:00-15:30 and is facilitated by two Waverley Care peer-support staff members. The number of group participants varies from three to fifteen women each week depending on factors such as the weather or personal circumstances. The group begins over tea, coffee and snacks to discuss the events of the women's past week and to explore issues that influence their emotional, physical, and mental health. An artist is then introduced to the group who guides the women through a creative art project. The group facilitators select art projects based on the women's input and interests.

The concept of community empowerment was apparent and has been realised by engaging the group in decision making over the years, from choosing the group's name to drafting and amending the group agreement. The women were encouraged to share any problems or concerns as they arise and to submit ideas for future creative art projects. Examples of recent creative arts projects included ceramics, mosaic tiles, and jewellery making. The women also had opportunities to participate in other activities hosted by Waverley Care and attend weekend 'residential' retreats.

At the time of this research, the women were engaged in a six-week project focused on the goddess Venus and historical representations of the female body. In the 18th and early 19th centuries, a sexualised anatomical Venus functioned as a dissection model for male doctors (Bates, 2008). The women of Isis were creating their own interpretation of Venus to reclaim

their identities as patients back from the patriarchal gaze of medicine. The final collaborative art piece will be exhibited at the Surgeon's Hall Medical Museum in Edinburgh.

4.2 Background on Study Participants

All of the seven Isis group members I interviewed had been participating for several years, although one woman did not answer this question because she could not remember exactly when she began. Two women had been participating for 20 years and the remainder had participated for 17, 15, 10, and 8 years respectively. Three of the women were in their 40s, two were in their 50s, one is in her 60s, and one is in her 70s. The self-identified ethnicity of five of the women was Scottish. One woman self-identified as "British-white" and immigrated to Scotland in 2000. Another woman self-identified as Barbadian and immigrated to Scotland in 1979. In terms of education levels, four women had completed high school level, two women had completed post-secondary level, and one woman had completed post-graduate level. The domestic status of six of the women was either single, separated, or divorced and one woman was recently engaged to be married. Three of the women did not have children, one woman had one dependent child, one woman had two dependent children, one woman had two non-dependent children, and one woman had five non-dependent children. Three women were unemployed and received disability benefits, one woman was employed part-time and received disability benefits, one woman received a Jobseeker's Allowance, and two women were retired and received a senior's pension.

4.3 Stigma & Social Isolation

Dealing with the stigma associated with HIV was a topic that dominated the women's narratives and it contributed in significant ways to their social isolation. The women were all older in age and this has been found to exacerbate social isolation and access to social support (Groves et al., 2010; Emlen, 2006). Quotations from participants highlighted the prevalence of intersecting systems of vulnerabilities and marginalisation, which was not only attributed to their HIV status but also to factors such as their gender, sexual identity, age and socio-economic situation. For example, when Pyrite was first diagnosed with HIV, she perceived it to be an "ugly, difficult, and scary disease" and did not believe that the new drug treatments on the market would work. She described the stigma associated with HIV as affecting those in society who were already marginalized because they were gay, drug users, prostitutes, or from ethnic minorities. When asked to describe what social isolation meant to her, Pyrite responded:

It means that you feel that you're not actively engaged with the community around you, that you don't either feel that you've got friends or that you can contribute to the society that you are in. And to me, it's sort of loneliness.

Pyrite felt that loneliness is no longer her problem, in part due to her participation in Isis, but when she initially received her diagnosis she withdrew from society. Amethyst remembered experiencing social isolation before attending Isis because she had no social support network and limited education about the disease. At that time there was no treatment available and as indicated in her comment below, she thought she was close to death.

Because you believe what you read and what you hear, and when you see people around you dying that were a lot younger than you, you think - well my turn will be soon. And I thought I was going to die soon, and there was nobody you could talk to, I didn't have a partner, I'd never been married and all that. And my parents were old, all my brothers and sisters were away getting married and children and working.

4.3.1 Fear of Disclosure

Social isolation can arise out of self-inflicted fears of disclosure and the subsequent rejection that can prevent women from seeking support networks (Hackl et al., 1997; Judgeo and Moalusi, 2004). This was highlighted when Topaz feared disclosing her HIV status and the subsequent rejection that could ensue. Women may also conceal their status by instead focusing on their child's needs. For example, Topaz described her social isolation as a "big burden" because she kept her status a secret for 15 years before sharing it with her daughter. This finding was consistent with research on the binary of women as being both an HIV patient and a mother (Hackl et al., 1997). Similarly, Celestite initially worried about not building trusting relationships because she feared rejection if she accidentally disclosed her health status. Now she prefers to tell people about her HIV fairly early in a relationship to witness the person's reaction before she has developed feelings for them. She thought this cautious coping mechanism helped safeguard her from the loss of relationships and verbal abuse, which supports Gielen et al. findings (2000).

An interesting finding of this study was that although disclosure is usually associated with negative consequences (Carr and Gramling, 2007), sharing experiences of stigma due to HIV served as a foundation to the Isis group. Sapphire felt disclosure created the strong social bonds because: "We all have the link of knowing what it feels like to have that stigma or fear of stigma and being judged and looked down upon." This finding suggested that disclosure

can also have positive consequences when done in a supportive environment with others who suffer from the stigma and social isolation associated with HIV/ AIDS.

4.3.2 Low Self-esteem

The fear of rejection resulted in low self-esteem, as was evident when Ruby said she was frightened about people knowing about her illness. She also felt very alone and did not feel good about herself. This reflected Goffman's (1963) definition of stigma, where the rejection of others "spoils normal identity" (p.3). Because Ruby believed she had a terrible disease, she retreated from society, as she described in the following quotation.

I just sat about and didn't want to do anything. I think I thought my life was ended. And they put me into a counselor. She was lovely, and she introduced me [to the support group]. It was called Solas then. Ya, it was up at Ivy Mound. She took me up there. They had a wee cafe and I had a cup of tea and met [the group's facilitator]. But it was about three or four weeks before I had the courage to go up myself and go back.

4.4 Isis: Key Strengths of the Weekly Creative Arts-Based Support Group

A gap in the existing literature is that it inadequately considers the role the creative arts plays in support groups for women living with HIV/AIDS. Data from the narrative interviews revealed that the women were extremely positive about Isis and this helped to explain their long-term involvement in it. The support group was called Isis after the powerful Egyptian goddess of health who, according to myth, breathed life into and resurrected her husband's mutilated body (Knapp, 1996). Group members felt Isis symbolised how HIV had torn apart their lives and how the weekly support group has helped them piece it back together. All of the women remarked how powerful it was to collaborate on naming the group and this suggests the compelling function that a community empowerment approach and a concrete symbol served for the group's connectedness.

The key strengths of Isis identified by participants included the nonjudgmental environment, confidence and self-worth building through creative art projects, creative arts as therapy, confidentiality policy, financial support, longevity and flexibility of attendance, social support, advocacy, and engagement outside of Isis.

4.4.1 Nonjudgmental Environment

Isis was designed to provide a sense of collective space where interpersonal relationships were forged to gain strength and improve self-worth. Six of the seven women identified the

nonjudgmental environment as a key strength of Isis. Ruby explained that the nonjudgmental environment included listening, understanding, and being supported by “the most amazing people I have ever met.” Like Ruby, Topaz felt a major strength of Isis was its nonjudgmental environment, which she described as: “All the ears are open, shoulders there to cry on, arms are open, ready for a cuddle. I think everybody needs that.” Amethyst described “loving” Isis and she experienced a sense of relief when first learning that every female participant in the group had HIV [or Hepatitis C] because: “Everybody was the same as you, nobody was any better or any lower, we are all the same.” She described Isis as a welcoming and judgment-free space for women to share weekly activities, problems and worries.

Ruby said the nonjudgmental support provided by the Isis group made her feel good about herself and this has been transformational because it “gave her her life back.” She said her children also love Waverley Care because they know their mother would probably not be living such a healthy and full life without it: “You know, I think I would have just faded away and gave up. But, look at me now!” Amethyst also reflected on what her life would be like without Isis: “It has done a lot because maybe if I didn’t have somewhere to go, somewhere to share my feelings freely and all that, where would I go?” As discussed in the next section, this is partly because the nonjudgmental nature of the support group was a stepping-stone for building the women’s confidence and self-worth.

4.4.2 Confidence Building & Self-worth

All of the women expressed how Isis creative art projects instilled a sense of accomplishment and enhanced their confidence, which supported Baumgartner’s (2002) findings that social interaction is transformational for building confidence in women living with HIV who are in a stigmatised state. Improving confidence is one facet of individual characteristics that intrapersonal level interventions seek to change (Heijnders and van der Meij, 2007). When describing her recently completed projects, Amethyst said she never imagined that she could make such “pretty art.” The group had inspired a new sense of achievement and independence in her when she said: “The group has made me realise that I’m not as stupid as I thought I was.” Another participant expressed how engaging with challenging creative art projects allowed them to release their creative potential while boosting their confidence.

All of our art and craft, you know, we get to take it home. And you actually find out how creative you are. It brings it out of you. And if

people comment, it puts your confidence up. And I get a lot of confidence, they all say I'm good at it. I like a challenge, you see. I won't do something simple (Topaz).

This finding aligned with how one of the group's facilitators, Emerald, conceptualised confidence building through a community empowerment approach. While Emerald strove to respond to the group's needs, she also felt a responsibility to encourage the women to try new art projects that were outside of their comfort zones, because this was where the biggest gains in confidence could be achieved. However, it was essential that the preparation behind creative arts projects was apparent to ensure that the women feel respected and valued. The group's other facilitator, Sapphire, commented on how she sometimes felt that the art facilitators were inadequately prepared for projects: "Oh great, we're doing that again because they've run out of ideas." Although it is difficult to accommodate the diverse expectations for an art project in a group setting, Sapphire believed that encouraging the women's creative gifts led to enhanced confidence and self-worth.

4.4.3 Creative Arts as Therapy

Aldridge (1993) proposed that the restoration of hope is critical for HIV treatment, and two of the women identified this as a key strength of Isis. In terms of transformation, the creative arts offered the potential for self-discovery and change that at best, refracted out into the rest of their lives. Jade provided an illustration of this when she said she loved the project that she was working on for the Surgeon's Hall Medical Museum and was looking forward to a future mosaic mural the women will be creating on the side of a medical clinic. Jade's sense of achievement from the creative arts also extended into her dream of one day becoming a paramedic: "Life's for living. I set my goals. And I'm just ticking them off." According to Celestite, the creative arts offered her an opportunity to explore her feelings and create something new. She really enjoyed making art and found the process to be therapeutic because it allowed her to take her mind off her problems. She added that some people do not like to see a therapist or share their feelings verbally, so the creative arts can serve as an alternative therapeutic method. This was another example of how Isis operated on an intrapersonal level of intervention (Heijnders and van der Meij, 2007).

4.4.4 Confidentiality

Four of the women identified confidentiality as another key strength of Isis. Amethyst described the group's strict adherence to confidentiality as: "What goes on in the group stays

in the group.” Onyx, an arts facilitator, felt the anonymity of the building’s entrance was important for women who are experiencing stigma and social isolation. For Jade, confidentiality also meant security and having peace of mind because she would not like to have anyone talking about her or disclosing her status to someone outside of the group. Jade explained how all the women respected the group agreement and sometimes discussed and updated them accordingly. For example, the group had a “no cellular phone policy” and Emerald, one of the group’s facilitators, felt restricting the outside world from intruding on the group was essential for creating a safe and confidential space. The importance accorded to confidentiality also emerged in Pyrite’s account of how women in the group decided on the following cover story to the outside world to prevent their HIV status from being disclosed: “We met through doing the mosaic class, which is finished, so you can't join!”

4.4.5 Financial Support

As indicated in the preceding summary of financial support received by Isis group members, none of the women were employed full-time and only one of the women was employed part-time. It was therefore crucial to consider the financial support that assist women in accessing Isis, which four of the women identified as a strength. For example, Garnet felt it was very important that her bus fares were reimbursed which meant she could come and “sit in a room for two and a half hours and have fun with really nice women which is great!” Isis membership, the arts projects and refreshments are also provided for free.

4.4.6 Attendance: Longevity & Flexibility

Another key strength identified by four women was Isis’ long history and flexibility of attendance. Celestite thought it was good that the group has lasted for so long because many women would otherwise be much more socially isolated. She explained how this could particularly affect women who live further away or those who do not meet up with the women outside of the group.

Perhaps one reason for the longevity of the women’s attendance, participants also highlighted the ease and flexibility of attendance. This is another programme strength because the women felt there is no pressure to make a time commitment and they were free to attend as often or as little as they pleased. This was also tied to the nonjudgmental environment discussed earlier, as Amethyst explained.

But Isis has always been there. You know, even if you didn't come, in a few months or a few years, you can just walk in. And kind of not be judged - she hasn't been here for a few years, what is she doing coming back? People are just happy to see you.

Pyrite expressed similar sentiments when she commented: "I had been coming all the time, but I have missed months and months and months at a time. That's the advantage of it not being a formal, sign-up for six week course and sign out again." She explained that while some member's attendance may be irregular, there was a really interesting and supportive core group whose attendance was reliable. One of the group's facilitators, Sapphire, commented how she was aware when someone does not show up for awhile, so she would reach out with a non-pressuring phone call to check in on them.

In terms of funding groups based on outcomes, Pyrite said that the women's long-term attendance could appear as a lack of success for Waverley Care because they continue to access services. However, she claimed the stable core group enabled other women to either join the core group, come and go as they please, or move on from the group. Pyrite stressed that support is an on-going process and the women should not be held to a standard "where they are cured and then forced to move on from the group".

Two participants reported the group had previously discussed the disadvantages of meeting during a weekday afternoon because it excluded women with normal working hours. This could potentially still be a constraint for some women. Alternative times or dates, such as evenings and weekends, had been debated over the years. Occasionally, the group had held evening activities but the time change did not attract new participants. Instead, those in attendance were the same women who were already engaged in the afternoon sessions. Pyrite believed it is important for the women to know that if it is a Tuesday afternoon, there will be a support group meeting. This would make it easier for women to attend because if the date and time are unstable, women may start to forget or face confusion. Jade thought that a lack of structure was a major weakness of a different support group she had attended in Glasgow, and she argued that the consistent meeting time combined with flexible attendance was a key strength of Isis.

4.4.7 Social Support

All seven Isis participants perceived social support as being key in helping them cope with stigma while reducing their social isolation. The social support was thought to be unconventional in nature because it focused on other things, such as the current art project with the Surgeon's Hall Medical Museum, rather than just focusing on their illnesses all the time. As Pyrite explained:

I think when you hear about peer support groups where people just go and talk about what it's like to be living with this illness or something and you feel like why on earth would you really want to depress yourself by listening to that all the time? Like, people can raise that, but that's not what it's all about.

Coming to value other parts of their lives is another way women in Isis coped with stigma. For example, Celestite claimed she can say anything to anyone in the group at anytime. She made the following comment about how excited she was to be able to share good news despite having HIV.

But all I can say is that it was really nice to come in today, to tell people that I had been engaged. It was really lovely to have that reaction, for everybody to be really pleased for me. And it just goes to show that you never know what can happen! You know? It's not the end of the world [to be HIV-positive]!

Topaz defined social support as "just being there for somebody and knowing that somebody is there for you." She felt that when she put a smile on somebody's face, she received joy in return. To illustrate, Topaz shared a powerful experience of receiving peer support from an Isis friend that she has had for over 20 years.

She [her friend] helped me write a letter, I can feel the tears coming on. She helped me to write a letter to explain to my Mom before she went and passed away. But that was me getting it off my chest, my status, you know? That's how gentle they can be, these people. My friend did that for me, and she's gone through the exact same thing as me. But the fact that she could sit back and put up writing for hours so I could tell my Mom? That's a true friend.

Celestite regarded the peer support aspect of Waverley Care to be very helpful for newcomers who may be very isolated and afraid to face a larger group initially. Newcomers are met by facilitators and/or one or two Isis members before hand, which prevented them from having to enter the group alone. Emerald, one of the group's facilitators, pointed to the value of having long-term members of Isis who are living full and healthy lives to reassure newcomers and potentially act as sources of inspiration. However, she noted that sometimes long-term members of Isis find it difficult to revisit their past memories of initial HIV

diagnosis, in part because they have moved on from the pain and stress associated with that time in their lives.

Ruby expressed how impressed she was that Waverley Care was able to find such amazing and supportive staff and board members, who were also part of the social support network. To illustrate, when Jade and her partner were trying to conceive a baby, she was supported by Waverley Care and nurses at the hospital. She had given birth to two healthy children who are HIV-negative and considered Waverley Care and the women of Isis “to be just like family now”. Topaz described one of the group’s facilitators as a “goddess” and explained how she supported her through hardship: “[She] was there for me when I lost my husband. [...] Ya, so they’re not here just for, because you have HIV. You know, they’re here for anything else that goes on in your life as well.” The integrated services offered by Waverley Care ranged from support for women raising children to financial advice, and illustrated how the intrapersonal and interpersonal levels of intervention in Heijnders and van der Meij’s (2007) framework can be effectively intertwined to provide non-stigmatised health care services.

While the social support offered by the Isis group was considered a key strength, some members were uncomfortable discussing personal problems, so they may have felt more socially isolated compared to those who did. For example, Garnet reported she did not want to access support from the group when she was struggling because she found it hard to trust people: “They [Isis group members] can be so upbeat, you don’t want to go and sit in the middle of that with your big blah and bring it all down.” This illustrates how some women are embedded with the instinct to care for others by not wanting to be a burden (Hackl et al., 1997). Onyx, an art facilitator, noted that “it’s also in what people don’t say as well” because some women spoke often of their families while others did not mention anyone at all. This could be because some women’s confidence has risen and they feel more free to talk about themselves or their family may have rejected them (Carr and Gramling, 2007).

4.4.8 Advocacy

Another key strength was identified when five women explained how they had journeyed from a state of social isolation to take on advocacy roles to help others in the community who were also experiencing stigma and isolation. Part of this advocacy role involved raising awareness about the benefits of Isis and this illustrated how participation in the group can radiate out to the community level (Heijnders and van der Meij, 2007). For example,

Amethyst has introduced many women to Isis and recounted how she brought one isolated grandmother in to give her a break from her daily stressors. Amethyst hoped that she has raised awareness about Isis in the community because she considered it to be “such a great group.” However, she also mentioned that support group remains inaccessible to many women in Edinburgh, so outreach is constantly needed.

Jade has spoken publicly about her story of living with the stigma of HIV and believed that she has inspired many people because her illness did not prevent her from being able to give birth to her healthy children. When someone expressed interest in joining the group, she would tell them:

We’re very welcoming. We’re there for the same reasons that they’re going to be there, to support them. At the end of the day, we were in their shoes once upon a time. It’s like driving. We were all learners once.

Ruby is another Isis member who was at a point where she wanted to give back to the community. She self-identified as “a normal healthy pensioner now”, but remembered her earlier struggles with stigma and social isolation. She recalled her experience when she spoke publicly at a community event as follows.

When they asked me if I would tell people about what is wrong with me, [I agreed]. Because you know, I’m not ashamed of it, you know, it’s an illness just like any other. I haven’t done anything wrong. And, so I thought, ya, I’ll talk. So we went to Glasgow and I can’t remember what it was called, but they do bucket shaking after events. And they asked me if I would talk at it and after they said they’ve never gotten as much money before.

Ruby strongly felt that if someone was recently diagnosed with HIV, they should not become an isolated recluse. Instead they should: “Just come and join us [Isis]! Come and see us, we will love you!” In another example of advocacy, Pyrite self-identified as being both an activist and service user who is concerned about HIV globally.

And because of the 15 years of friendships [in the Isis group], because I’m still committed to people with HIV having access to treatment, I’m still concerned about being active on HIV issues in the world, so from both sides I want to support people with HIV but make it also the issue about HIV worldwide.

4.4.9 Engagement Outside of Isis

An additional aspect of intrapersonal, interpersonal and community levels of intervention in dealing with the stigma of HIV (Heijnders and van deer Meij, 2007) was apparent when all seven of the women explained how participation in Isis was a window into other social

activities run by Waverley Care and out in the community. One participant had found employment with Waverley Care and was particularly excited by this opportunity. Other organisational activities that members participated in included the service user involvement group, the walking group, the befriending group, yoga, meeting with women for lunch and engaging in other social events together.

All of the women expressed how much they enjoyed going away on weekend outings organized by Isis that they referred to as 'residential'. Amethyst explained how none of the women wanted to leave their most recent getaway near Loch Lomond and she described her experience there as follows.

I kind of really enjoy it. I remember we were away a couple months ago, it was great, all the women just getting away. No television, no music, great communicating, socialising, a bit more socialising at night.

Jade described the residential as being a respite from everyday life where she could connect with her "great group" thereby further reducing her social isolation. She was excited for the upcoming residential trip to the Highlands that ten women would be attending. Ruby recalled a London theatre trip and reflected on how she would never have had this experience if she did not know the women of Isis. However, having the confidence to go on one of these trips can be challenging for some, as Celestite acknowledged.

I was going through quite a bit of emotional stuff obviously after having been diagnosed. So I was really quite quiet and shy. Just like I am now [both laugh]. But ya, I had lost confidence as well. But it was really nice to go and meet, to get to know some of the people a bit better. The first one was a bit scary, but it was lovely as well. And then as I got to know the people, then it was fine. It was actually like you looked forward to going away once a year. They usually have the money to go away for a residential.

Topaz also described residential as an opportunity to "just get away from reality" where one can interact with others without the fear of stigma. Topaz said residential enabled her to participate in "things that bring you together" such as art projects, relaxation sessions, group walks, and free time. She explained that none of the women are pressured into participating in any of the Isis or other Waverley Care activities, although all of the women are encouraged to join in. Topaz appreciated it when people brought new activities to the group that she had never experienced before. For example, she enjoyed participating in a session on happiness where the women exchanged compliments about each other. Topaz's favorite

residential art project inspired each woman to represent their interests on a life-sized outline of the female body.

4.5 Key Limitations of the Programme

When asked if they had any recommendations for Isis, five women responded that they could not think of any improvements for the group. For example, Topaz felt it was quite hard to make any recommendations: “No, I don’t know what I could say to improve it.” Because Isis is largely directed by the female members themselves using a community empowerment approach (WHO, 2014), the women felt free to speak up to a group facilitator or other group member if a problem arose. To illustrate, Jade explained how she approached an issue: “Look, this just happened and this shouldn’t be happening. Yep. And I’m quite an outspoken person, if I’ve got something on my mind, I’m going to say it!” Celestite could not think of any way Isis could be improved other than increasing the group’s funding. She also said that because of the group agreement written by the women, if a problem arose, it is dealt with directly. Ruby responded that the group was great just the way it is: “I think that we are unique, that we are the only one.” Garnet felt that I was lucky to have had the opportunity to conduct research with the group because:

If you ever have to set up a group, you have a really good precedent. You’ve got, you know that it can work, you’ve seen it work, and you know what molecules you need to put together to get the whole. And really great women, I’ve bet you’ve had a great time.

While all seven women were overwhelmingly positive about Isis, four weaknesses were identified that included overcoming the stigmatisation of the other Waverley Care’s women’s support group held at Milestone residential centre, raising additional funding, creating social spaces that promote social interaction and constructing a wheelchair accessible facility. While most of the group did not see the need for major improvements, this does not account for the changes that may be needed to include those who remain outside the group. This includes those who are not aware of the program, and those who face greater barriers to participation such as having a mental health and disability, living in communities that are far away or being non-English speakers.

4.5.1 Overcoming Stigma

Waverley Care also has a women’s support group at Milestone Residential and Outreach Support Centre that offers intensive residential support. After spending time with both groups, one woman felt that women at Milestone were stigmatised by some Isis members.

Amethyst explained how Isis women received preferential treatment and are “spoiled” compared to the women at Milestone. She suggested that perhaps, the difference lay in the mode of HIV transmission: “I don’t know if it makes a difference, but a lot of the women here [at Isis] have caught the virus from sex. Whereas up at Milestone, most of them have caught it from being intravenous drug users.” This finding supported research on the multiple layers of stigma and how some women experience greater levels of it for being drug-users (Sandelowski et al., 2004). Amethyst suggested that the stigma could be overcome by increasing the interaction of the two support groups: “I think sometimes it would be good for the Thursday group and Tuesday group to get together and do a project or something.” Although Amethyst acknowledged that the women at Milestone have greater needs than the women at Isis and therefore may not be able to participate in some of the same activities, she suggested that the artists who facilitate Isis projects should spend equal time with the women at Milestone.

4.5.2 Financial Barriers

Three of the women identified financial costs to joining (e.g., for lunch, trips, and other social activities) that may dissuade women outside the group from joining. They also pointed to the importance of continued funding that is integral for Isis and the arts projects to continue. In the past, the weekly support group’s funding has been cut which subsequently limited the activities the women were able to participate in.

4.5.3 Location

Three of the women said that the old location for Isis, called Solas, was superior to its present location at Mansfield Place. Because Solas was located within a spacious drop-in centre setting, the women enjoyed having social space to eat lunch, have tea or coffee, and meet with the other women. Celestite considered herself to be the only woman who actually liked the new premises at Mansfield Place because “it’s brighter and lighter.” Amethyst felt that having access to cheap and healthy meals was a major strength of the old Solas facility. A possible suggestion to continue the meal program with Isis would be to encourage local restaurants to donate and deliver lunches before the group each Tuesday. The meal program would also overcome the financial barrier posed to some women who cannot afford to meet for lunch before Isis. Although Waverley Care had to find a new location because the lease was up at the old facility, it was suggested that the organisation find or create social spaces that better facilitate social interaction.

4.5.4 Wheelchair Accessibility

While only two women mentioned it, the lack of wheelchair accessibility at Waverley Care was another key limitation because women with mobility problems are excluded from participating. As Amethyst explained:

I don't understand why they picked these offices. [...] It's stupid, being down here. I know a few people, one of the girls in the Thursday group she's in a wheelchair sometimes, I mean, she couldn't come here. The doors aren't wide enough to get a wheelchair in. It's a bit stupid.

This issue has been debated over the years and has not been addressed due to lack of funding. Nonetheless, it presents a barrier to many people in Edinburgh to overcome social isolation and access services from the organisation.

CHAPTER 5: CONCLUSION & RECOMMENDATIONS

Overall, there was strong consensus about the strengths of the weekly Isis support group and how participation in it was transformational in helping women cope with stigma of HIV and reduce their social isolation. Prior to joining Isis, the women expressed fear of disclosure and how this contributed to low self-esteem. The weekly support group offered a forum for women to disclose and share experiences, challenges and celebrate strengths and achievements. The arts projects provided the women with an embodied experience and the opportunity to connect with other women through creative exploration. For most of the women, group participation ‘radiated out’ and instilled the women with the confidence to try new activities and build new relationships in other Waverley Care programmes and in the community.

The key strengths of Isis that contributed to its positive appraisal by women who were long time participants included: a nonjudgmental environment, confidence building and self-worth, creative arts as therapy, confidentiality, financial support, longevity and flexibility of attendance, social support, advocacy, and engagement outside of Isis. While Isis is a small programme, qualitative evidence directly from women living with HIV illustrated how it spanned and interconnected the intrapersonal, interpersonal, and community levels of intervention (Heijnders and van der Meij, 2007). In terms of the intrapersonal, Isis improved individual self-esteem, coping skills, and confidence. These intrapersonal benefits were enhanced when the interpersonal level encouraged social support networks and a nonjudgmental environment where confidentiality was adhered to. Advocacy and engagement outside of Isis illustrated the ways that Isis participants extended the reach of the programme into the community level.

These are characteristics of the program that should be reinforced, maintained and expanded upon where possible. Future research should also be conducted to determine if these programme characteristics are beneficial in other contexts and for other sub-groups living with HIV. This type of evidence would be very helpful for other health organisations and policy makers and would provide a strong rationale for devoting more resources and policies dedicated to similar community-based support groups. Without the continued funding for facilities and a community empowerment approach such as Waverley Care that provide services to people who are socially isolated, researchers, health practitioners, and policy

makers will fail to understand the effects of stigma and social isolation because they will not be working with these groups to inform practice (HIV Scotland, 2013). In many ways, Isis can serve as an exemplary case study for replication and continued funding.

While most of Isis members did not see the need for major change, four limitations identified by long term members included finding ways to overcome stigma against women who have contracted HIV through drug use, raising additional funding, increasing social spaces to enhance interpersonal connections, and making the space wheelchair accessible. Other recommendations for improvement should be elicited through further research with those who have ceased attending or with women who face greater barriers to participation (e.g., drug users, women with disabilities, women who live in isolated communities and non-English speakers). Waverley Care has a responsibility to better articulate their support group practices to attract additional participants, secure ongoing support from partners, and to serve as a model for other community-based health promotion programmes. Communicating its structure, method of operating, and benefits of participating on the Waverley Care website, through outreach and in written documentation that is made available through other community groups is highly recommended. As the women's narratives in this study were powerful and some Isis members have reached a point where they are comfortable with public speaking and disclosure, providing additional opportunities and support for the women to communicate their stories and the benefits of participation in Isis would enhance the community level of intervention (Heijnders and van der Meij, 2007).

While there is a growing body of literature on HIV and social isolation, a gap remains on the role of support groups with a creative arts component in helping women with HIV overcome social isolation and deal with the stigma they encounter in society. This study provided evidence of the benefits of the creative arts for women living with HIV. It is beneficial to continually ask how the Isis group is making a difference to woman's lives to foster greater accountability and transparency of practice. The findings also pose implications for the development of policy directed at the role of support groups in HIV healthcare. It is through focusing on the needs of the women that groups like Isis can uphold the human right to a life of dignity and respect whereby women living with HIV can freely access treatment, care, and support.

In addition, it is crucial to explore what structural mechanisms are needed to combat the pervasive stigma against women with HIV in society (Heijnders and van der Meij, 2007). While the women's agency, support groups like Isis and organisations like Waverley Care are essential, the reduction of stigma that leads to social isolation and poor health should not be up to them alone to ameliorate.

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APPENDIX I: DEMOGRAPHIC CHARACTERISTICS

Years of Involvement with Isis	Age	Self-identified Ethnicity	Scottish Born? Check if yes.	If no, when did you immigrate to Scotland?

Please check all that apply. If other, please specify:

Education Level		Domestic status	
High school		Married	
Post-secondary		Single, separated, divorced, widowed	
Post-graduate			

Parenting	
Children? Yes/No	
# of dependent children	
# of children not dependent	

Financial Support	
Social assistance	
Disability benefits	
Seniors pension	
Supported by partner	
Unemployment	
Part-time employment	
Full-time employment	
Unknown	
Other (please specify)	

APPENDIX II: CONSENT FORM

CONSENT TO PARTICIPATE IN ‘A Critical Appraisal of HIV Healing for Women through a Creative Arts Support Group at Waverley Care’

I understand that I have been asked to participate in a research project being conducted by Kelly Frisby of the University of Edinburgh’s Global Public Health Unit, Global Health and Public Policy (contact info: +44 7941 644626 (c); s1459539@sms.ed.ac.uk) under the supervision of a Dr. Anuj Kapilashrami of the University of Edinburgh’s Global Public Health Unit (contact info: Anuj.Kapilashrami@ed.ac.uk).

A. PURPOSE

I have been informed that the purpose of the research is as follows ... (*Please state the purpose of the research clearly and concisely, in no more than one or two sentences*).

B. PROCEDURES

In consistent, “I understand” format, please indicate in this section where the research will be conducted and describe in non-technical terms what the participants will be asked to do, the time required to do it, and any special safeguards being taken to protect the confidentiality or well being of the participants.

C. RISKS AND BENEFITS

In consistent, “I understand” format, please indicate in this section all potential risks of participation, and any benefits of participation.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.
- I understand that my participation in this study is:

CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity)
- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

DATE _____

I understand that I have been asked to participate in a research project being conducted by Kelly Frisby of the University of Edinburgh's Global Public Health Unit, Global Health and Public Policy (*contact info: +44 7941 644626 (c); s1459539@sms.ed.ac.uk*) under the supervision of Dr. Anuj Kapilashrami of the University of Edinburgh's Global Public Health Unit (*contact info: Anuj.Kapilashrami@ed.ac.uk*).

If at any time you have questions about your rights as a research participant, please contact Kelly Frisby, s1459539@sms.ed.ac.uk