

Cervical Cancer Prevention & Treatment in Merseyside for Women Living with HIV

A THEMATIC ANALYSIS OF THE PERCEPTIONS OF WOMEN LIVING WITH HIV

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Foreword from the author

The following information does not aim to cause alarm in those who are living with HIV or HPV infections. It is important to note that cervical cancer is one of the more preventable cancers and can take years to develop. Although having either of these infections raises your risk of cervical cancer this is by no means inevitable.

In fact, by attending routine cervical smears, medical professionals can monitor and treat abnormal cervical cells before they develop into the cancerous or even pre-cancerous stages. One of the aims of this report to lessen the fear and stigma surrounding cervical cancer and instead raise awareness and understanding of it in those who are more prone to this preventable disease.

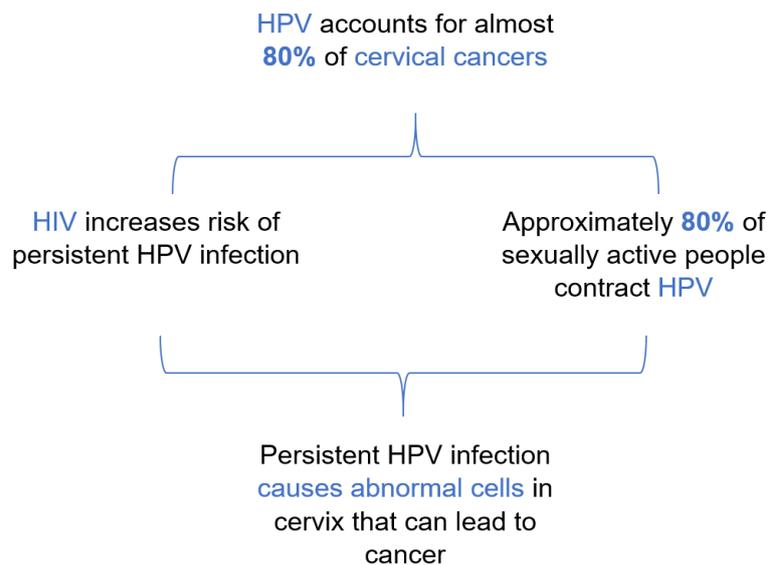
The relationship between HIV, HPV and Cervical Cancer

Cervical cancer is a major global health problem, rated as the fourth most common cancer in women [1]. The Human Papillomavirus (HPV) is the cause of nearly all cervical cancers as it causes cells in the cervix to develop abnormally [2]. If untreated, over time this can lead to cancer [3].

HIV, HPV and cervical cancer rates are strongly correlated for a number of reasons [4]. HPV infection can double a woman's risk of acquiring HIV as it causes lesions in the cervix and vagina, which act as transmission sites for the virus [5].

For those who already have HIV, due to their impaired immune system their bodies have a harder time fighting the HPV virus and are more prone to persistent HPV infections (which can lead to cancer). Therefore, women living with HIV have a higher risk at developing cervical cancer and cervical cancer develops even faster in HIV positive women [6 & 5].

The following diagram illustrates a summary of the relationship between HPV, HIV and cervical cancer:



Due to how common it is to contract HPV and its relationship with cervical cancer, it is imperative that all women (age 25-64 in the UK), not just those living with HIV, attend their cervical screening routinely so that the health of their cervical cells can be adequately monitored.

There are varying stages of cervical cell abnormality, from mild changes that your body can fight off itself without treatment, to moderate and significant changes which if untreated can go on to develop into cancer. Therefore, routine smears help to prevent cervical cells from developing into pre-cancerous cells, and also provide opportunities for earlier treatment if cancerous cells are found.

In fact, the risk of developing cervical cancer for women living with HIV is decreased to the same level as those who are not living with HIV if they are routinely screened [7]. Like with many cancers, the earlier cervical cancer is found the better the outcome is for the patient.

Why this research was conducted

According to Public Health England (2018) HIV is still an important public health concern in the North West, with this region accounting for nine percent of the UK's new HIV diagnoses. Of the estimated 8,682 individuals living with HIV in the North West, 26% of these are women [8]. Past research has shown that women living with HIV face additional barriers to cervical cancer prevention and treatment due to their HIV status [9]. Therefore, it is imperative that the cervical cancer prevention and treatment services available to this population are perceived and experienced as adequately accessible to them, in order to encourage the prevention, early detection and treatment of this disease.

There is limited up to date research and information on the perceptions and experiences of women living with HIV of cervical cancer prevention and treatment in Merseyside. This signifies a gap in not only the academic knowledge but could also mean that the healthcare system and its delivery (including patient and healthcare professional communication) might not be meeting this population's needs. In order to address these issues, first the experiences of women living with HIV in Merseyside need to be understood.

Therefore, this research aimed to further the understanding of the barriers and facilitators of health behaviours surrounding cervical cancer prevention and treatment for women living with HIV in Merseyside. This was done by exploring their experiences and perceptions of cervical cancer and its prevention and treatment.

This report aims to benefit Sahir House and its service users as it can be used to gain a deeper understanding of these individuals' experiences and perceptions and perhaps highlight areas for improvement in terms of cervical cancer prevention and treatment in this population.

This research gave individuals from minority groups a voice and a chance to highlight any potential issues that may exist with regards to cervical cancer prevention and treatment in their population.

How the data was collected

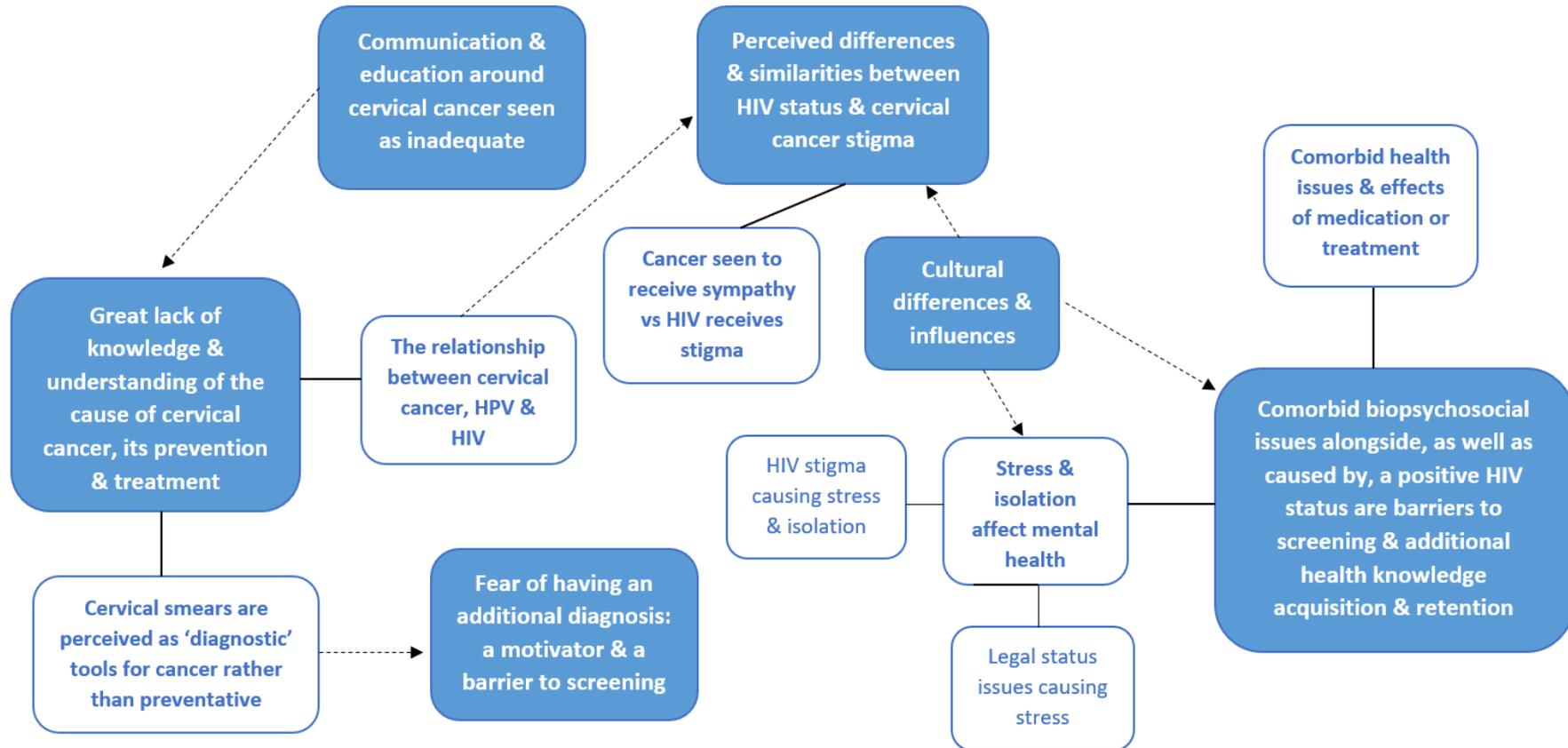
Ten women living with HIV over the age of 18 living in Merseyside were recruited by using Sahir House's social network and participants were invited to take part in the study at Sahir house.

Semi-structured, one to one, audio recorded interviews were conducted in a private setting (Sahir House). Audio data were stored on a password-protected computer and file and then transcribed. All the women were provided with participant information sheets to take home with them and written consent was given by the women before the recorded interviews commenced.

Recordings were deleted and data was analysed using thematic analysis (a further description of the analysis process can be seen in Appendix 1). Participants' data was anonymised.

Thematic Map illustrating findings

Six main themes (three of which had subthemes) were identified from the data which are illustrated in the thematic map below. The thematic map gives an overview and also illustrates how these themes and their subthemes relate and influence each other.



Comorbid – another word for co-existing or occurring at the same time

Biopsychosocial – the biological (e.g. HIV), psychological (e.g. anxiety) and social factors (e.g. stigma) that can influence or contribute to an issue

Narrative and discussion of themes

Theme 1: Great lack of knowledge and understanding of the cause of cervical cancer, its prevention and treatment

Despite the fact that this population is particularly at risk of developing cervical cancer, their knowledge of what cervical cancer is was very low, with the majority of the responses being similar to the following:

I am not informed at all; I don't know nothing about it. [...] To be honest with you I haven't got a clue. I just know there is a thing called cervical cancer but I don't know any more about it. (Participant 2)

None of the women had knowledge about survival rates of cervical cancer, and in fact there were some that perceived a diagnosis of cervical cancer as terminal such as the following:

For that I don't know. I don't know. What I know is for cancer there is no medicine for cancer. You just have to protect yourself, so that you won't get that disease, but it is difficult, anyway I can't say. (Participant 5)

The difference between HIV and cancer, is cancer you know when you will die. That is the problem. Because the doctor if he will tell you after 6 months you will die, after one year, in two years, that is the worst, he will count it now. (Participant 9)

This comparison between HIV and cancer was made often, where HIV was perceived to be more manageable and a less terminal diagnosis. This is perhaps due to the fact that these women are living with HIV, whereas none of them had had any personal experience with cervical cancer. Only one of the women who works as a nurse had seen patients with cervical cancer which had been diagnosed in the later stages and the affected patients suffered painful deaths.

The majority of the women viewed cervical cancer as the same as other cancers whereby the earlier it was discovered and treated the better the outcome was for the patient.

Those that spoke about stages of cancer attributed their knowledge to either their educational background in health sciences (two of the participants were healthcare professionals) or reading they had done on their own.

When asked about what treatments they thought were used for cervical cancer, those that did reply applied what they knew about treatments for cancer in general such as chemotherapy and surgery.

All the women expressed that they felt they were not alone in terms of their lack of knowledge surrounding cervical cancer and that they felt they shared this with the general population:

I mean it is interesting that I feel like I have had no information having had this conversation with you but I have probably had more information than other people...because of the spaces that I put myself in. So, I could be in research spaces and I could be in other spaces where other women wouldn't be. So, I think I have got some more information but actually I feel woefully lacking in information [...] so I think that is a general sense of where women are at. (Participant 3)

The relationship between cervical cancer, HPV and HIV

Most of the women assumed that they had to attend screening due to their HIV status. However, none of them could explain exactly what role their HIV status played in cervical cancer other than it might have to do with their impaired immune system making them more susceptible to cancer.

I imagine being HIV positive, and I know that there's more susceptibility towards cervical cancer if you are HIV positive and I imagine that is due to an inflammation response, from... it can happen around an inflammatory condition such as HIV. Um, and that is all I know. (Participant 3)

Knowledge surrounding the causes of cervical cancer was also very low. Again, many of the women applied their knowledge of causes of cancer in general:

I have no idea what causes it, what causes any cancer? I know things that...like smoking. Doesn't mean you are going to get cancer, but it doesn't help at all or ... like with throat cancer and that sort of thing, but really...I don't know what causes cervical cancer. (Participant 4)

While others had other theories from lack of hygiene to trauma as seen in the following comment:

I haven't got much knowledge on cervical cancer, what it is and how it might be caused. So, I imagine it might be caused by trauma... (Participant 3)

A few thought it might be linked to sexual intercourse and possibly a sexually transmitted infection (STI):

I wouldn't have another guess apart from what I said earlier. But I don't know if maybe like sexually transmitted diseases can like intensify or maybe make the chance high, or maybe being sexually active, I don't know. That one I will have to learn. (Participant 6)

Oh yeah, I know, for the woman... I think that one is like us who live with HIV, when we make sex unprotected, when we make sex unprotected the first, and the second maybe the man who I slept with maybe he had STD disease, like...you know...[...]it's transferred diseases by sexually, I don't know by English...if someone has something like that, or if I go...if I go with different men without protect (protection), I think it is going to cause for the cancer. (Participant 9)

In fact, only one of the women mentioned HPV as being a cause of cervical cancer:

I know that ...think a predisposing factor is the HPV virus, that is the Human Papillomavirus virus, and that um, and it is only detected by having a smear, and then the smear will show some abnormal cancer cells in your cervix, for us who are HIV positive, we have to have the smear once a year, it has to be yearly. (Participant 7)

Interestingly, although Participant 6 initially said she was unaware of what caused cervical cancer, once the author asked whether she was aware of HPV and explained that it is one of the main causes of cervical cancer she realised she had misunderstood what HPV was prior to the interview:

I think I am now trying to distinguish between...because before, I don't know why I was thinking that the HPV is the cancer itself ha ha! They are two different things, it has just clicked in my head now. (Participant 6)

However, neither of these women understood how HPV caused cancer or abnormal cells. Worryingly, there was one participant who had abnormal cells in a smear test, yet was still unaware of HPV or what causes abnormal cells:

Well I am not so sure really, because they never get to diagnose...they just say you have irregular cells, so that was when they were checking it. So, like now I have to go every year for cervical smear. (Participant 10)

Cervical smears are perceived as 'diagnostic' tools for cancer rather than preventative

When asked about prevention none mentioned the HPV vaccine. When the author asked whether they knew about it only a few had ever heard of it. There was a widely held perception that the only medical preventative was the smear test such as the following:

Yeah, the prevention is the smear test, if the only prevention they have is the smear test it is good but they should try remind women to quickly go in for it. (Participant 1)

However, when asked how they thought the smear test prevented cancer, it was evident that all except one woman perceived the smear test as 'testing' for cancer. The preventative role smear tests were seen to play was that of preventing the cancer progressing by 'catching it in time' or 'early' rather than preventing the development of cancer in the first place. As mentioned, the concept of 'the earlier the cancer is caught the better' was held by almost all the women with comments such as:

I thought the smear was just to catch it in time. (Participant 4)

If they do the smear test, for women, quickly, and they get the cancer immediately, before it spread, they can pull through it. (Participant 1)

Yeah and I think it can be treated if it is seen early, so somebody should be going for smear test, so if it is caught early, I think it can be cured. (Participant 8)

None spoke about or were aware of procedures for pre-cancerous cells. This is probably due to the fact that nearly all were unaware there are stages of cell abnormality before they turn cancerous.

It is imperative that this perception of the smear test being a diagnostic tool be corrected as, combined with cervical cancer being seen as a terminal diagnosis, a lot of fear was attached to smears that the women felt could act as a barrier to screening for other women. For example:

I think they wouldn't want to know. Like the same like... HIV, some people they don't go for test because they are scared. (Participant 5)

They don't want to know. Because it is something that is scary as in 'I have got this now, so later I am going to die' so they don't want to know about it, that is why they don't want to go for test. (Participant 7)

Although only two women reported having to encourage another woman to go for screening, both reported that it was indeed fear of diagnosis that had been the barrier to screening:

Because she was afraid you know 'I am alright not knowing' rather than going to have a smear test and being told... [...] They were scared. They were afraid, that terror, that they will find out that they have cancer. (Participant 7)

Theme 2: Fear of having an additional diagnosis: a motivator and a barrier to screening

That concept of...and having a second thing to deal with on top of your HIV can be very distressing.
(Participant 3)

Interestingly, living with HIV and the vigilance one needs to have with regards to their health was often quoted as being the reason the women attended their screening appointments.

People who live with HIV, we tend to take more care of ourselves once we have that diagnosis. A lot of the girls I see, even the guys [who are living with HIV], they want everything tested, whereas to get my brother to even go get his sight tested is ...never mind to get him to go and get his prostate done. (Participant 4)

So yeah you would have to be very careful if you want to live, so you have to really look after yourself, don't miss appointments, when they tell you, you go, it is for your own good.
(Participant 8)

Those that said they went for screening as they feared having an additional diagnosis were those that viewed the smear test as being able to 'catch the cancer early'. Therefore, the fear of having an additional diagnosis was more related to fear of having a diagnosis that required more intensive treatment, with comments such as:

I don't waste time, once I see the letter, I will even book the appointment before the time that they gave me. I like to move ahead, because already as I am now, this bag you see me carrying, it is not about beauty, it is full of medication, so I have a lot already, I don't want to add more.
(Participant 1)

However, the women worried that although their HIV status was a motivating reason to go for their screening, the fear of an additional diagnosis might in fact prevent others living with HIV from attending screening:

I just think any kind of form of cancer, it is just one of those things isn't it, is scary on top of another...depending on what time you received your HIV diagnosis in the time line of the HIV, it may have been framed as a terminal illness and cancer at times is framed as a terminal illness and you know that double trauma, that is a difficult thing to deal with. (Participant 3)

The women felt that if other women better understood the role of the smear in cervical cancer prevention as they did after the interview, that this would help lessen the fear surrounding screening. They also said that with this understanding, they felt more empowered to encourage others to attend screening.

Theme 3: Perceived differences and similarities between HIV status & cervical cancer stigma

I think HIV is still seen as a Sub Saharan disease, and it's still seen as for people who are homosexuals. You know, they don't realize that it affects anyone, anybody. (Participant 7)

Unfortunately, all of the woman spoke about the prevailing stigma towards HIV in today's society, both in the UK and African communities. Those who were from African cultures felt this stigma is more prevalent in their African communities here in Merseyside, and even more so in their African countries of origin. However, the two White British women that were interviewed also felt that HIV stigma is still prevalent in UK society and therefore they either did not disclose their status or were very careful with whom they talked to about it.

Although they felt it was not seen as being as stigmatised as HIV, the women did go on to express that due to the cervix being seen as a sexual organ it was still seen as taboo topic to talk about, especially in some African cultures.

I think it is similar to how I feel about HIV being stigmatized because it is something sexual, because it is sexual organs. (Participant 4)

Whether it is because it is seen as a taboo topic or just not something people think to talk about, all the women mentioned that cervical cancer was not something that they discussed amongst themselves at Sahir House. For example:

Because I am new here in Liverpool, I have only been here...I have been living here since I think from April (interview took place in August). So I don't really know many women many people, even the ones I meet here in Sahir House we don't really speak about...it's 'Hi how are you?', that's it, we don't talk about anything we don't go into personal stuff, although we come here to the same place that we know is HIV, nobody knows... you can assume that I am HIV, I can assume you are HIV we don't discuss these problems so I don't know . (Participant 2)

Many spoke about how in their African community cancer is generally not spoken about but not explicitly due to stigma, however the lack of willingness to talk about the illness was similar to that of HIV. There was one woman who described stigma towards cancer in her African culture in general but not specifically cervical cancer:

That is what I grow up with, it is the culture, the shame , if me I have a cancer, my daughter, no one can marry her, they believe on that, they say of her mother she had a cancer so if I marry her, maybe my children they will get the cancer, something like that. They don't know even that the cancer is different, different kinds different types [...] If a mother has a cancer, she don't tell even her husband [...] so she can't tell her friend, her family, even her husband. Until she die. So, she don't take a treatment she just wait to die. That is you know, so this kind of culture, how can you change it? It takes time. (Participant 9)

She went on to say:

That is why you didn't hear in a Somali or Eritrea, someone who has cancer, they just keep quiet. You never hear, me since I come, I never hear, one [person from her country African country], I know all the [people in her community from her African country], but I never hear someone who has cancer. They make hide it. (Participant 9)

Cancer seen to receive pity vs HIV receives stigma

The women frequently mentioned how they felt it was easier for someone to disclose they had cancer compared to HIV as cancer did not carry the same stigma, and instead received sympathy. When asked why they thought this was answers were similar to the following:

It is because HIV, I think, my thought is because it is linked to sex. And cancer is not linked to sex. Because most people don't know anything about the HPV and how it is transmitted. (Participant 7)

There are many kinds of HPVs in addition to the ones that cause cervical cancer. Some cause other cancers such as throat, while others cause noncancerous growths like the common wart or genital warts [10]. One of the participants disclosed that she had the HPV that causes genital warts and said she felt she had experienced HPV related stigma due to the visible nature of this kind of HPV and in fact had also been self-stigmatising. Like the other women she felt people tend to be more sympathetic towards cervical cancer and this may be the lack of understanding that it is caused predominantly through an STI.

It appears people's lack of knowledge surrounding cervical cancer and how it can be caused by a sexually transmitted infection (HPV) might play a protective role against stigma.

Interestingly, this is not the case in Sub-Saharan countries where mortality rates (death rates) of cervical cancer are high (11). Although there is little understanding of the causes of cervical cancer in these countries, it carries stigma similar to HIV as it is seen as being a 'dirty disease' a 'prostitute's' or a 'promiscuous woman's' problem.

Therefore, this is an issue to consider when educating such communities about the causes of cervical cancer. If it is understood that cervical cancer is predominantly caused by an STI, there is risk that this might inadvertently attach stigma similar to HIV to this disease. It might be important to first normalise and educate people on how common and easily contractable (due to it being transmitted skin to skin) HPV is so that it is not simply associated with being 'dirty' or 'promiscuous'.

Theme 4: Cultural differences and influences

Yeah, it's different here from...from here in England, and in Africa, when you see that someone has got cancer or HIV you don't talk about it. But I learn here you can talk and you can ask questions. (Participant 5)

As mentioned, those of African origin felt the UK society was more liberal and constantly attributed this to lack of knowledge in their African communities. They felt this lack of knowledge was expressed with regards to cervical cancer and not just HIV.

There were also discussions amongst many of the women who were from African countries as to how any cancer diagnosis is perceived as terminal in their countries of origin, due to the lack of resources and access to good healthcare:

[African country]? Cancer? Anybody who has cancer in [African country] is dead! Who will treat you? They don't even know what treatment is all about. I don't trust their medication because many of their tablets they have there is chalk, fake! So you won't even have access to it, that is the problem, and moreover the rich don't survive it [...] So, it's like a death sentence (HIV), likewise cancer, cancer is even the worst. (Participant 1)

In my country if you are sick, that is it, you just to go to the church to pray. Or to wash holy water because you don't have any choice. If you are rich you go to Sudan, or Rwanda for treatment. But it is easy to...you can see many people die because of cancer. (Participant 9)

It was also discussed how that perception can be maintained and perpetuated even within the African communities that have developed in Merseyside. Some of the women also talked about the lack of integration of their African community and how being so isolated can perpetuate such perceptions and lack of knowledge and non-screening behaviour. For example:

They will go (to cervical cancer screening). If they understood. Our people you know most times, they only go to work and then go to home, they go to the restaurant and only speak my language, if you are only talking my language your brain is not going to grow up. At least if you meet another from Liverpool or from Africa or from Europe or from anywhere, you know you can learn many things, but our people our community is just go work and home, when they are free they just go to the same restaurant just speaking our language just talking about politician or something about our country. So how do you know, how do you remember about the smear. They don't read a book, they don't ask people. (Participant 9)

Others spoke of similar issues and of how, in their culture, the younger generation learnt from the older generation. Therefore, if the elders lacked knowledge of cervical cancer this was passed down the generations, especially for those who were isolated within their African community.

Others, including the two White British women spoke about the indignity (especially in a more modest culture) of having to be bare from the waist down and expose yourself as being a barrier to screening.

Some spoke about what encouraged them to go for their HIV tests and that a contributing factor was the cultural change from their country of origin where HIV was viewed as a terminal diagnosis whereas in Europe it is viewed as manageable.

Yeah because I have seen people dying in front of me. People I worked with, dying in front of my eyes you know. And I thought if I have got it I don't want to know. (Participant 7)

Perhaps if educational campaigns could reach these more secluded communities, similar changes in the cultural perception of cervical cancer might be achieved which could lead to uptake of screening.

Theme 5: Comorbid biopsychosocial issues alongside, as well as caused by, a positive HIV status are barriers to screening and additional health knowledge acquisition and retention

I have so many other things going on, so not only our capital letter H I V! I have many things going on! (Participant 1)

As a coping mechanism to the stresses in their lives the women described having to be protective of themselves in what they take on mentally. They have to reserve their cognitive abilities and are selective about what information they take in or can allocate attention to, otherwise they can become overwhelmed.

I don't put my mind there. Thinking about cancer, or anything about cancer, I don't know... (Participant 1)

Because the more I know, I will be panicking, so at least I need to know what is important just to understand. (Participant 10)

I like to ask especially if I know I lack that information, but if I don't need it at that time I don't need to ask because I have a small brain so I can't fill up my little brain with a lot of things I don't need at that time... (Participant 6)

Many talked about how the stress they experienced on a daily basis limited their capacity to absorb and retain information:

You see everything you are telling me here now, I am very sure I have heard it, trust me my brain...I don't remember things easily, I easily forget things, so I am sure I have heard many things about this HPV...if you ask me now when you finish what did you say about HPV...I will not remember again, I easily forget things . (Participant 1)

I think it is that my mind is not focusing on so many things at the moment, it is just too stressed. Even when I am reading something, it doesn't stay in my mind so...[.] As a matter of fact, just last week when I went to my GP, the nurse, I went for the TB injection or something like that and then she spoke about that, the cervical cancer, wow to be honest I can't remember! I was listening...but you know it just goes in and it goes out. (Participant 2)

Stress and isolation affect mental health

Feelings of stress and isolation were commonly expressed by the women which were seen to affect their mental health, memory and ability to concentrate at times. In addition, some spoke about how their stress and mental health was sometimes a barrier to screening:

I have to feel mentally strong enough to go for a screening or appointment. (Participant 3)

HIV stigma causing stress & isolation

Because there is some people when they hear a person's situation they don't close their mouth, they will announce everywhere they go. So, you can't be happy, when you are moving in the street when you are going, you see people they are talking about you. Yeah. Because in Africa, when someone has got a HIV they say she is or he is a prostitute! But yet, that is not the reason. (Participant 5)

Many of the women have faced incredibly challenging experiences which have impacted their mental health. The constant fear of their community finding out about their HIV status is seen as yet another

thing they have to deal with. For those that already feel isolated, or that they cannot talk about their past or current struggles for fear of the stigma that might be attached to it, this becomes even more isolating.

Not really...not a topic ...apart from this stigma that we are carrying about with this HIV, that is like a problem to us. Though HIV, that you cannot discuss with somebody that you have sickness, it is just a hell of a problem. (Participant 1)

In fact, a few said that the only people they talked to about their HIV status and their problems were those at Sahir House.

Those that still had family in their countries of origin also stressed about someone in their African community in Merseyside disclosing their HIV status to them. They felt that due to the stigma still attached to HIV and the perception of it being a death sentence, they wanted to protect their family from the shame, stigma and worry of their situation. Not being able to share their struggles with their family caused further isolation.

As in many African countries there is a stigma attached to cervical cancer and this too could be a barrier to screening (due to fear of diagnosis) and isolation from support during treatment for those living in such communities in Merseyside.

Legal status issues causing stress

A few of the participants were asylum seekers who are living under very stressful conditions due to their legal status in addition to their HIV status and comorbid conditions. They described how this had an impact on their mental health and cognitive abilities such as the following:

I have a lot of stress, in fact the Home Office, the last letter I received from them, when my case worker was talking to me I went off (zoned out), I was just looking at her, trust me I don't know what I am doing, this lady that brought me here (Sahir House staff member) she counselled me several times, tried talk me back, I even tried killing myself, I won't lie to you. So, since then they stopped sending me letters, because my brain can go melt, easily. (Participant 1)

She went on to say:

I am going through a lot, the Home Office is stressing me, [...] every day I am on [treatment for an additional condition], my papers is not yet out, I am living in a shared accommodation [...] because if they send me back, it is like, my dear you go home and die! Because there is no hope in back home, I don't trust them! [...] at the moment to be honest, it is not only the knowing about cervical cancer, it is about everything, my mind is just not focusing (Participant 1)

For some their asylum seeker status had caused them to be homeless. Worryingly, two of the women stated that there had been years that they had not been screened even after their HIV status was known as they were unable to register with a GP, or had been moved so often the health services had not organised for them to be screened. One of them described being so sick due to her homelessness

that she had nearly died. This is very concerning as stressful conditions such as these have been shown to affect the immune system [12] which, hypothetically if these women had the HPV, combined with their HIV status would have made them even more susceptible to persistent HPV infections which can lead to cervical cancer.

Comorbid health issues and effects of medication or treatment

As with many people who live with HIV, the women spoke about the challenges and complications that accompany this disease, both physically and mentally. A few of the women spoke about other health conditions they had, some of which they thought were consequences of their Antiretroviral medication (HIV medication) or HIV. Some of the women reported having comorbid health issues in addition to their HIV status.

A few of the women spoke about how their medication and treatments affected their concentration and ability to understand information. Healthcare professionals, or anyone delivering health information to this population should bare this in mind. For example, one of the participants spoke about a nurse telling her about cervical cancer related information but she was unable to follow the conversation:

I didn't really understand because I was just coming from my [treatment for another condition]. And you know I was so drowsy. (Participant 1)

Others spoke about how comorbid psychological disorders such as Post-Traumatic Stress Disorder (PTSD) affected their ability to learn new information:

I have to live with that for the rest of my life. Yeah so, my concentration levels and my levels of absorbing knowledge are not what they call they normal. (Participant 6)

It was clear that for the women to improve their knowledge on a topic they had to be motivated and to make a conscious effort to do so.

Theme 6: Communication and education around cervical cancer seen as inadequate

All of the women felt the raising of awareness and understanding of these issues should be improved. Common modes of health education campaigns were suggested, such as the need for pamphlets in GP surgeries and advertisements through media (e.g. radio, television), although interestingly many of these already exist. Based on the lack of knowledge in this sample of women, it seems the pre-existing health education surrounding cervical cancer is either ineffective or in need of improvement.

Perhaps it is the content of the educational material that is lacking in effectiveness rather than the methods with which they are distributed. There seems to be a need for lay and more accessible explanations (especially in minority, harder to reach groups) surrounding the causes of cervical cancer

and its prevention and treatment methods. In fact, many of the women that came from such minority groups described the need for more outreach educational programmes, particularly due to the cultural issues previously discussed. One woman discussed how such communities might be more receptive to such conversations if it was facilitated by an interpreter:

So some people they need to go to their house, to go with their language, there are different languages [...]Also if you go for, for example in the [an specific African community] community, if you go for one woman, with an interpreter, if you explain for her nice, she will tell for her friend. And her friend she will tell another friend, they will become more better at thinking about it. If you go to a [another specific African community] community, you go with interpreter [that speaks their language], you talk with one lady, or two ladies, they will tell each other, they will tell another friend, so they will become, I think they will become more interested. (Participant 9)

These methods have been shown to be effective in other health education interventions, such as the use of community educators, particularly when medical staff resources are limited. However, if such topics are seen as taboo, there may be difficulty in recruiting such community educators or interpreters, especially when minority groups can be such tight knit communities. Nevertheless, this has been achieved in other areas of health education and if such taboos or stigma is to be broken, these barriers would need to be, or at least attempted to be addressed.

There were also suggestions that attempts to raise awareness and educate people on cervical cancer should be made in nonmedicalized settings (such as in shopping centres, at bus stops and in schools) so that talk about cervical cancer can be normalised. It was also pointed out that if such educational material is limited to medical settings it would not be reaching those that do not even make it to these medical settings.

And because it is not visualized anywhere so in train stations, on boarding (bill boards), on bus stops, on taxis, I don't know, not ever, you know inside a magazine never on the front. That, when people see something like that it becomes normal and it becomes less, you know, less frightening if it is out there. (Participant 4)

It was also apparent that there were missed opportunities for the women to receive clarifying information from their health care providers. Although they all said that they thought their nurses, GPs or consultants would explain if they asked, they felt that the healthcare professionals simply did not have the time to, or it was 'not their job' or they felt gatekept by the receptionist as seen in comments similar to the following:

Because I think people think they are pestering the GP. You know because you can get gatekept now and quite often you don't want to talk about, well I don't want to talk about those kinds of issues with the receptionist. But maybe we really really do need to do that and be empowered to do that. So maybe that is just my approach towards the receptionist. (Participant 3)

I think they are fabulous the NHS workers, I just think they are struggling to see everybody... (Participant 4)

I don't know, because there is the next patient waiting to go in. You know, rushing for time. That would be good when you go for the smear. It would be good if they sit you down, but I don't think they have got 5 minutes to preach to you. (Participant 7)

Others thought that the nurses did not feel the need to talk to them about the reasons for them having to come for a smear as they assumed, by turning up to appointments, they knew already.

It was evident with accounts such as the following that the current system with which these issues are dealt with results in a lack of adequate communication and understanding:

Yeah I think that the second last, the last...the last one that I went to they sent me to the Women's hospital, to do a smear test, I have never been there before, that was my first time. And when I did it, they said it has, something stage, I don't know what stage. There were about 3 nurses there, but one was just facing the computer while the other was attending to me. They only say, they will send it back to my GP, but I ring several times to my GP but I didn't get the...I didn't understand what the result is all about...I saw one letter, it's a long time but I can remember, but I know I had a letter in the house. (Participant 1)

Those that said a health professional 'might' have given them information regarding why they should attend smears admitted they either could not remember if this conversation had happened or they were unable to retain or understand the information. This indicates that perhaps the healthcare professionals either did not explain the relationship between HIV, HPV and cervical cancer in a manner in which they could understand; did not have time to check if the patient understood; or were not aware of what mental or physical state the patient was in and whether they were well enough to acquire and retain verbal information.

When asked whether they preferred to have information delivered verbally or in writing the women said it depended on how they were feeling at the time. While there were benefits to written information which they could access when they felt up to it, relying solely on written communication had its downsides.

Considering the coping mechanism employed by the women not to overwhelm themselves with information or topics that might be stressful, if the responsibility to seek out this written information were left to the women there is a danger that they would not do so.

Therefore, it would seem should more accessible written information be provided, it should be delivered directly to these women to digest in their own time and not rely on opportunistic encounters.

When talking about educating the public a few of the women talked about the usefulness of mobile phones as pamphlets are not always kept or tend to get lost:

*Maybe printing out a big something like this *points to information sheet*, a big paper and place it like in the SAHIR House for women, most women they come here, or some other organization, maybe at the hospital, you put it there, gum it all over (stick), you know those who will pass will read it, if you can't stand and read it while you are there, thank God for a smartphone, you can easily snap it and the woman can read it in the time she can...[..] I think it would make women really understand more, not only people living with HIV, general women, we are all women no matter if we have a big stigma on our forehead. (Participant 1)*

All of the women said that they felt more informed and had a better understanding of this relationship and the need for smears after having had a conversation with the author. For some, it was the first and only in-depth conversation they could remember having had on the topic. When asked why they thought a healthcare professional had not had such a conversation with them some replied with:

Maybe because everything was in that little leaflet, but trust me I don't have time to read. (Participant 1)

This might indicate it would be even more effective for the women to be able to have conversations with an informed individual, whereby questions can be asked and clarifications given, rather than passive one-way information delivery.

Conclusion and Recommendations

Current delivery of HPV and cervical cancer education in this population seems to be inadequate.

Although the sample for this study was small, based on findings reported other research (13), it can be suggested that the issues discussed in this study might not be limited to the ten women that were interviewed. Further research would be needed to explore this further.

Nevertheless, based on the findings of this study the following recommendations can be made:

- Educators (including healthcare professionals) should be aware that women living with HIV might face additional challenges regarding knowledge acquisition and retention and adapt accordingly (e.g. asking intermittently if information has been understood and providing easily accessible materials they can refer back to at a later date)
- When providing one-to-one or group cervical cancer education, more focus should be given to the timing of such education, with an emphasis on appropriately presented lay explanations (not merely informing) of the HPV, HIV and cervical cancer relationship, as well as treatment and prevention measures. Where possible such education should allow for interaction between the educator and the recipient/s to maximise understanding and information retention.
- An important message that should be promoted is how preventable cervical cancer is and that smears are preventative measures, not necessarily diagnostic tools, to alleviate the fear surrounding smears that may be a barrier to screening. To aide this message it should be clearly explained that there are varying stages of cell abnormality and these can be treated even before they get to the pre-cancerous stage.
- There is a need for cervical cancer education outside of the medical setting to break taboo and be able to reach those that do not make it as far as the GP or hospital for screening.
- More outreach educational programmes are needed in minority groups and communities. Especially for those which come from countries where the healthcare system and lack of education means lack of understanding and stigma may be even more prolific. Educational programmes should be tailored to the community it is delivered to and the use of community educators could be made due to the shortages of NHS staff such as community nurses.

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References

1. Bhadelia, A. (2019). Evidence for the path to cervical cancer elimination. *The Lancet Global Health*.
2. Berman, T. A., & Schiller, J. T. (2017). Human papillomavirus in cervical cancer and oropharyngeal cancer: one cause, two diseases. *Cancer*, 123(12), 2219-2229.
3. Sado, A. E. (2019). Mathematical Modeling of Cervical Cancer with HPV Transmission and Vaccination. *cancer*, 4, 14.
4. De Vuyst, H., Alemany, L., Lacey, C., Chibwesa, C. J., Sahasrabudde, V., Banura, C., ... & Parham, G. P. (2013). The burden of human papillomavirus infections and related diseases in sub-saharan Africa. *Vaccine*, 31, F32-F46.
5. Ng'andwe, C., Lowe, J. J., Richards, P. J., Hause, L., Wood, C., & Angeletti, P. C. (2007). The distribution of sexually-transmitted Human Papillomaviruses in HIV positive and negative patients in Zambia, Africa. *BMC infectious diseases*, 7(1), 77.
6. Gaffing, S., & Gupta, N. (2016). Cervical cancer screening in HIV positive women. *European Journal of Surgical Oncology*, 42(11), S236.
7. Massad, L. S., Seaberg, E. C., Watts, D. H., Minkoff, H., Levine, A. M., Henry, D., ... & Hessol, N. A. (2009). Long-term incidence of cervical cancer in women with human immunodeficiency virus. *Cancer*, 115(3), 524-530.
8. Public Health England (2018). Annual Epidemiological Spotlight on HIV in the North West 2016 data. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/681443/HIV_Spotlight_NW_2016_data.pdf
9. Gordon, J. R., Barve, A., Chaudhari, V., Kosambiya, J. K., Kumar, A., Gamit, S., & Wells, K. J. (2019). "HIV is not an easily acceptable disease": the role of HIV-related stigma in obtaining cervical cancer screening in India. *Women & health*, 1-14.
10. Brondani, M. A., Siqueira, A. B., & Alves, C. M. C. (2019). Exploring lay public and dental professional knowledge around HPV transmission via oral sex and oral cancer development. *BMC public health*, 19(1), 1529.
11. Williams, M. S., Kenu, E., Adanu, A., Yalley, R. A., Lawoe, N. K., Dotse, A. S., ... & Fontaine, K. (2019). Awareness and Beliefs About Cervical Cancer, the HPV Vaccine, and Cervical Cancer Screening Among Ghanaian Women with Diverse Education Levels. *Journal of Cancer Education*, 34(5), 897-903.
12. Arranz, L., de Vicente, A., Muñoz, M., & De la Fuente, M. (2009). Impaired immune function in a homeless population with stress-related disorders. *Neuroimmunomodulation*, 16(4), 251-260.
13. Allen, G. (2004). Reducing women's fears and anxieties about smear tests. *Nursing in Practice*. Retrieved from: <https://www.nursinginpractice.com/article/reducing-womensfears-and-anxieties-about-smear-tests>.

Appendices

Appendix 1: The Six Steps in Thematic Analysis

Step	Description of process
1. Researcher familiarises themselves with the data	Interviews are transcribed and re-read while simultaneously writing down the first few ideas relating to the research questions
2. Researcher generates initial codes	Initial themes of interest are noted across all transcripts and coded
3. Researcher searches for themes	Codes are collated into possible themes, first with individual transcripts and then across all data
4. Researcher reviews themes	Researcher makes sure themes relate to coded extracts across entire data set, a thematic map is produced
5. Final themes are defined	Salient themes and subthemes are narrowed down and named
6. Production of a report of the findings	Researcher selects the richest, most convincing examples of the extracts that supports the analysis and findings that related to the research questions