

# Ageing and menopause considerations for women with HIV in the UK

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## Abstract

**Objectives:** Treatment rollout has dramatically improved life expectancy for people with HIV and AIDS. Women represent a substantial proportion of patients in the UK (approximately one-third of patients in care are female according to the HIV Annual Report 2014). This study examines psychosocial and biomedical issues for women diagnosed with HIV in the UK, comparing those above and below 45 years of age to examine menopause and ageing issues.

**Methods:** Consecutive clinic attenders in a large outpatient London HIV clinic were invited to participate in the study. Data were available for 170 (68%) women. In 57 women above the age of 45 data were available regarding menopause detailed insights.

**Results:** Compared with women aged under 45, women >45 years old were significantly less likely to be in a relationship ( $P=0.01$ ), had higher anxiety scores ( $P=0.002$ ), more likely to be classified as moderate to severe (25.9% vs 9.1%;  $\chi^2=6.1$ ,  $P=0.01$ ). There were no differences in terms of suicidal ideation, which was high for both groups of women (56.6%). Older women had higher psychological symptoms on the MSAS scale form and significantly higher PHQ-9 depression levels. A higher proportion of older women scored above the cut-off point for moderate to severe depression (9.2% vs 21.8%;  $\chi^2=3.7$ ,  $P=0.048$ ). Fewer older women had no mental health challenges (26.1% vs 42.4%) and more had multiple comorbidities ( $P=0.07$ ).

**Conclusions:** The vast majority of women reported experiencing a variety of physical and psychological menopause-related symptoms and there was a high suicide ideation rate in both groups of women. Over half of the group of menopausal women recorded distressing symptoms such as hot flushes, sweating, decreased sexual desire, back pain, night sweats, avoiding intimacy, involuntary urination and skin changes, yet few sought help. Age-specific, psychosexual and menopause services should be routinely available for women with HIV.

Keywords: Women, HIV, ageing, menopause, mental health

## Introduction

In the UK, approximately one-third of people accessing HIV care are women [1]. There is a lack of data on the impact of HIV on women, particularly on the impact of HIV on psychosocial and emotional health. A limited number of studies and surveys have revealed some interesting gender differences in terms of the psychological effect of HIV. Women are reported to experience more shame and guilt over having HIV infection [2]. In a UK study, women had greater psychological and global symptom distress [3]. In that study, relational, sexual behaviour and quality-of-life factors were similar for men and women, and although adherence levels did not differ by gender they were sub-optimal in 56% of patients. Women with HIV have been shown to achieve lower scores in terms of quality of life than men [4–6] and HIV adversely affects their sexual activity [7–9]. These issues can have a negative impact on health-seeking behaviour, adherence to medications and clinical outcomes with HIV treatment [10]. Decreased sexual desire, poor sexual function and sexual inactivity are also common among women infected with HIV [11]. Coping strategies, ability to disclose HIV status to partners and to form new relationships as well as empowerment to practice safe sex may be affected negatively by HIV [9], though little is known about the current psychosexual challenges faced by UK women with HIV infection.

There is a growing literature on the HIV ageing population. The advent of highly successful HIV treatments, good adherence and improved side-effect management have resulted in a growing HIV population,

enjoying good health while being exposed to the natural processes of ageing. However, it is unclear how the ageing process affects people living with HIV compared to those without HIV, how it differs – or indeed if it does, and what service provision is required and available for this emerging population. Although many studies have explored men who have sex with men as they age, there is a dearth of literature on women generally and age-specific challenges particularly, such as menopause [12]. Menopause, and coping with ongoing menopause symptoms is a challenge for women generally [13], heightened for those facing HIV infection, especially given the ramification for sexual behaviour. HIV is now a chronic disease thanks to the advances in its treatment and subsequent dramatic decreases in morbidity and mortality. As a result, many women with HIV survive to experience menopause. There is some evidence to suggest that women with HIV infection experience increased menopausal symptoms and psychological concerns [14]. Yet a recent systematic review [12] could only identify six studies with conflicting and inconclusive findings. Of these, four were from the USA, one from Brazil and one from France. Thus there were no data from the UK. The present study addresses the lack of data on HIV and menopause in the UK for women with HIV.

In this cross-sectional study, we aim to explore the challenges faced by women with HIV in terms of psychosexual function, fertility, and their experience during menopause.

## Methods

Four research psychologists attended routine clinics in a large outpatient HIV clinic, the Ian Charleson Day Centre, Royal Free Hospital, London, and invited all women attenders to participate in the study. A total of 272 women were approached and screened for eligibility (age, language fluency, well enough to complete the

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questionnaire). Of the eligible participants ( $n=251$ ), 170 accepted to take part in the study (67.7% response rate). Usable completed questionnaires were received from 140 women (55.8% response rate from all approached). Among these women 57 were above the age of 45 and included in the menopause-specific elements of the study. Ethical approval was granted for the study (NRES 13/LO/1214).

### Measures

Participants were asked to complete a questionnaire about their HIV status, length of HIV diagnosis and treatment, psychosexual functioning and menopause. The questionnaire was constructed to include questions on demographic information, general health, standardised and validated scales on mental health and menopause measures, together with service and treatment availability and utilisation.

### Anxiety

Participants completed the GAD-7, a self-administered questionnaire used to measure anxiety [15]. The GAD-7 evaluates anxiety over the preceding 2 weeks by scoring seven questions on a four-point scale for a total score range of 0–21, with higher scores reflecting a greater severity of symptoms.

### Symptom burden

Symptoms included worrying too much, having trouble relaxing or being restless. Scores of 5, 10 and 15 are considered as the cut-off points for mild, moderate and severe anxiety respectively. Symptoms were measured using the revised Memorial Symptom Assessment Scale (MSAS-Short Form) [16], which has been used extensively in HIV populations [17,18]. Four positive items were added to counterbalance the scale negative effects, and included feeling reassured, optimistic, strong and supported. An item on the presence of suicidal thoughts was also added given the established elevated suicidal behaviours noted in the literature among HIV-positive respondents. On the standardised MSAS form, the frequency of all symptoms is scored as follows: 1: rarely; 2: occasionally; 3: frequently; and 4: almost constantly. The physical symptoms subscale is scored based on the frequency of the 12 most prevalent physical symptoms. Symptoms are rated on a five-point Likert scale (not at all: 0.8; a little bit: 1.6; somewhat: 2.4; quite a bit: 3.2; very much: 4.0). The inventory generates a Global Symptom Distress Index (MSAS GDI) and two composite measures (physical symptoms and psychological symptoms – MSAS Phys and MSAS Psych, respectively).

### Depression

Depressive symptoms were examined using the PHQ-9 Depression Test Questionnaire [19]. It evaluates the mood over the previous 2 weeks by scoring nine statements using a four-point scale (0: not at all; 1: several days; 2: more than several days; 3: nearly every day). The total score range in this study was 0–27, with scores of 5, 10, 15 and 20 representing the cut-offs for mild, moderate, moderately severe and severe depression, respectively.

### Menopause

Women above the age of 45 years completed the Menopause Specific Quality of Life questionnaire MENQOL [20]. This is the cut-off age generally considered for menopause-related issues. The questionnaire consists of 29 items in four groups: vasomotor: psychosocial: physical and sexual [21].

### Sexual functioning

Finally, women completed the Female Sexual Function Index (FSFI) – a self-report instrument [22] consisting of 19 questions from six groups: desire (2); arousal (4); lubrication (4); orgasm (3); satisfaction (3); and pain (3). The 19 items are evaluated for the

past 4 weeks. The total score for FSFI is the sum of scores for the six domains. Lower scores indicate greater severity of female sexual dysfunction (FSD). A score of  $\geq 23$  shows normal sexual function, 18–23 indicates mild FSD, 11–17 indicates moderate FSD and  $\leq 10$  indicates severe FSD [23–25].

### Analysis

Women of 45 years of age or over were considered to be in the menopause age band and were compared to those aged under 45 years to examine age-specific differences using one-way ANOVA tests and Chi-squared tests. In terms of the menopause-specific question data reported by 57 women eligible for this analysis, descriptive tests were used.

### Results

The group of women of 45 years of age or over was compared with the group below 45 years of age. The findings are set out in Table 1 below.

There were no significant differences according to age for ethnic origin. The majority of women (66.2% from the below 45 years of age group and 68.4% from the above 45 years of age group) recorded themselves as being of black ethnic origin. Similarly, there were no differences by group for education status. Residence in the UK was of prolonged duration, with a mean of 17 years for the former group and 22 years for the latter ( $F(1)=4.89$ ,  $P=0.03$ ). Average length of HIV diagnosis was approximately 12 years and differed by group (14 years for the older group vs 10 years for the younger group;  $F(1)=12.42$ ,  $P=0.001$ ). Older women were significantly less likely to be in a relationship ( $\chi^2(1)=6.13$ ,  $P=0.01$ ), and had higher anxiety scores ( $F(1)=9.57$ ,  $P=0.002$ ), with significantly more scoring above the cut-off point for anxiety classified as moderate to severe (25.9% vs 9.1%;  $\chi^2(1)=6.06$ ,  $P=0.01$ ). There was no difference in the distribution of suicidal ideation, but of note was the fact that over half of the women (54.1% and 56.9%, respectively) reported suicidal ideation in the previous week. Older women had significantly higher psychological symptoms on the MSAS scale as well as significantly higher depression levels on the PHQ-9 score. A significantly higher proportion of older women scored above the cut-off point for moderate to severe depression on the PHQ (21.8% vs 9.2%;  $\chi^2(1)=3.70$ ,  $P=0.048$ ). When examining mental health comorbidity, there was a tendency for fewer older women having no mental health challenges (26.1% vs 42.4%) and more having multiple comorbidities (two or three out of the three anxiety, depression and suicidal ideation – 26.9% vs 8.5%;  $\chi^2(1)=7.03$ ,  $P=0.07$ ).

The MENQOL questionnaire evaluates the number of symptoms women experience and the severity of each symptom. As shown in Table 2, the vast majority of women reported experiencing a variety of physical and psychological symptoms; however, the severity of symptoms was within the mild range. Over three-quarters felt tired (77.8%), 76.4% reported a lack of energy, 74.5% that they accomplished less than they used to, 72.7% a decrease in stamina, 71.4% weight gain, 69.6% poor memory, 67.9% difficulty sleeping and 67.3% wanting to be alone.

Distressing symptoms such as hot flushes, sweating, decreased sexual desire, back pain, night sweats, avoiding intimacy, involuntary urination and skin changes were noted in over half the group of older women. Of the 57 women, 35 had not sought help for their menopause symptoms. For those who had, this came from their general practitioner in four cases, the HIV clinic in 10, a gynaecologist in five, and friends in three cases. Most had not considered taking any treatment for these symptoms (35 out of 57). Only seven women reported taking hormone replacement therapy, while eight had used natural or herbal remedies. Five women reported using antidepressant

**Table 1.** Comparison of demographics and outcomes for women below and above 45 years of age

	Full sample (n=140)	Women aged <45 years (n=69)	Women aged ≥45 years (n=57)	$\chi^2$ or F(df), P value
<b>Ethnicity</b>				
White	34 (25.0%)	17 (26.2%)	16 (28.1%)	$\chi^2(2)=0.99, P=0.61$
Black	95 (69.9%)	43 (66.2%)	39 (68.4%)	
Other ethnic minorities	7 (5.1%)	5 (7.7%)	2 (3.5%)	
<b>How long living in the UK (years)</b>	M=19.30 (SD=11.29)	M=17.35 (SD=10.11)	M=22.44 (SD=13.13)	F(1)=4.89, P=0.03
<b>Education level (last qualification achieved)</b>				
GCSEs	22 (17.3%)	8 (12.5%)	11 (21.6%)	$\chi^2(4)=1.84, P=0.76$
A Levels	18 (14.2%)	9 (14.1%)	7 (13.7%)	
Degree	42 (33.1%)	22 (34.4%)	16 (31.4%)	
Postgraduate	23 (18.1%)	13 (20.3%)	8 (15.7%)	
Other	22 (17.3%)	12 (18.8%)	9 (17.6%)	
<b>Relationship status</b>				
In a relationship	67 (51.5%)	43 (64.2%)	22 (41.5%)	$\chi^2(1)=6.13, P=0.01$
Not in a relationship	63 (48.5%)	24 (35.8%)	31 (58.5%)	
<b>Length of diagnosis (years)</b>	M=11.54 (SD=6.43)	M=9.64 (SD=5.37)	M=13.74 (SD=6.76)	F(1)=12.42, P=0.001
<b>Anxiety GAD score</b>	M=4.64 (SD=5.34)	M=3.29 (SD=3.74)	M=6.15 (SD=6.28)	F(1)=9.57, P=0.002
<b>Anxiety GAD above cut-off point</b>	23 (17.8%)	6 (9.1%)	14 (25.9%)	$\chi^2(1)=6.06, P=0.01$
<b>Symptoms – MSAS Psych score</b>	M=6.34 (SD=2.81)	M=5.77 (SD=2.43)	M=6.96 (SD=2.84)	F(1)=5.38, P=0.02
<b>Symptoms – MSAS total</b>	M=25.59 (SD=5.18)	M=25.0 (SD=4.90)	M=26.25 (SD=5.25)	F(1)=1.87, P=0.17
<b>PHQ-9 score</b>	M=5.44 (SD=6.0)	M=4.00 (SD=4.28)	M=6.78 (SD=7.01)	F(1)=7.12, P=0.009
<b>PHQ-9 &gt; cut-off point moderate +</b>	22 (16.8%)	6 (9.2%)	12 (21.8%)	$\chi^2(1)=3.70, P=0.048$
<b>Suicidal thoughts in last week</b>	69 (56.6%)	33 (54.1%)	29 (56.9%)	$\chi^2(1)=0.09, P=0.85$
<b>Combined mental health burden</b>				
None (PHQ/GAD/Suicidal)	38 (33.6%)	25 (42.4%)	12 (26.1%)	$\chi^2(1)=7.03, P=0.07$
One out of three	55 (48.7%)	29 (49.2%)	22 (47.8%)	
Two out of three	10 (8.8%)	3 (5.1%)	6 (13.0%)	
Three out of three	10 (8.8%)	2 (3.4%)	6 (13.0%)	

Note: totals for some demographic data may vary due to missing data.

medication. Five reported using vaginal oestrogen cream and 23 reported taking medication for bone density.

## Discussion

Women attending a London HIV clinic tend to be of mixed ethnicity, with the majority recording black ethnicity, yet members of both age groups had resided in the UK for many years. The overall mental health burden for this group is of note – with many experiencing levels of anxiety and depression above the cut-offs and a high level of past-week suicidal ideation. The burden of HIV for women generally has been well recorded in the literature, and these data endorse these findings [26,27]. However, the women attending this clinic may have good access to specialised HIV and gender-related care, and this group may not generalise to all women with HIV [28]. Recent studies have indicated that there may be a burden of unmet need [29] and that the insight into challenges and provision for women is often skewed to focus on pregnancy with less literature on the totality of women's age range.

This small-scale study of female attenders of an HIV outpatient clinic in the UK's capital city shows the importance of age-associated burdens. A recent review has highlighted that menopause is an important consideration in the psychological health of women with HIV [30]. Menopause-related issues are particularly prevalent in this population and it is of note that there

is an unmet service need. Older women were significantly less likely to be in a relationship so the concerns of loneliness are heightened and the possibility of partner support reduced.

In terms of psychological burden, older women had higher anxiety scores with more scoring above the cut-off point associated with moderate to severe anxiety. This group of women had higher psychological symptoms on the MSAS scale as well as higher depression levels on the PHQ-9 score. A higher proportion of older women scored above the cut-off point for moderate to severe depression on the PHQ-9 Depression test questionnaire. When examining mental health comorbidity, there was a tendency for fewer older women to have no mental health challenges (42% vs 26%) and more to have multiple comorbidities (two or three out of the three anxiety, depression and suicidal ideation). Although age was not a factor in suicidal ideation, over half of all women in the study reported suicidal ideation in the previous week, which is extremely high and an indicator of life challenges faced by all women with HIV.

In terms of menopause symptoms, the vast majority of women reported experiencing a variety of physical and psychological symptoms; however, the severity of symptoms was within the mild range and the majority of women reported that they had not sought help for these symptoms or for their management. In the clinic where this study took place, there were dedicated menopause services available, but this is generally not the case in most HIV clinics, despite a growing need due to the ageing HIV population.

**Table 2.** Reported severity of menopausal symptoms experienced in the past month (MENQOL)

	Proportion of symptoms	Severity scale (range 1–8)
	n (% yes)	M (SD)
Feeling tired or worn out	42 (77.8%)	3.4 (2.0)
Feeling a lack of energy	42 (76.4%)	3.0 (2.1)
Accomplishing less than I used to	41 (74.5%)	2.7 (2.1)
Decrease in stamina	40 (72.7%)	3.0 (2.2)
Weight gain	40 (71.4%)	2.8 (2.3)
Experiencing poor memory	39 (69.6%)	2.6 (2.1)
Difficulty sleeping	36 (67.9%)	3.2 (2.4)
Feelings of wanting to be alone	37 (67.3%)	2.2 (2.1)
Feeling anxious or nervous	34 (63.0%)	2.6 (2.2)
Change in your sexual desire	33 (62.3%)	2.4 (2.6)
Being dissatisfied with personal life	35 (61.4%)	2.1 (2.1)
Feeling depressed, down or blue	34 (61.8%)	2.5 (2.1)
Night sweats	34 (60.7%)	3.0 (2.5)
Being impatient with other people	33 (60.0%)	2.9 (2.4)
Low backache	33 (58.9%)	3.2 (2.2)
Sweating	32 (58.2%)	2.9 (2.6)
Feeling bloated	32 (58.2%)	2.2 (2.2)
Avoiding intimacy	29 (58.0%)	2.4 (2.7)
Hot flushes	31 (55.4%)	2.8 (2.6)
Involuntary urination when coughing or laughing	30 (53.6%)	2.3 (2.5)
Changes in appearance, texture or tone of your skin	29 (52.7%)	1.9 (2.3)
Drying skin	29 (52.7%)	2.3 (2.5)
Vaginal dryness during intercourse	22 (44.0%)	2.1 (2.7)
Increased facial hair	23 (43.4%)	1.1 (2.0)
Flatulence (wind) or gas pains	29 (36.4%)	2.4 (2.0)
Aching muscles and joints	41 (29.3%)	3.6 (2.1)
Decrease in physical strength	40 (28.6%)	2.9 (2.2)
Aches in back of neck or head	38 (27.1%)	3.3 (2.2)
Frequent urination	28 (20.0%)	3.0 (2.3)

The majority of women in this study had not sought treatment options, despite often distressing symptoms.

This cross-sectional study gives some insight into the psychological burden in women. Despite the fact that older women recorded more burden on some of the variables, it is of note that there was high burden for the entire sample. It may well be that menopause is not the driving factor for such burden, but acts as an added complication to the many difficulties that women may encounter, including HIV diagnosis, treatment navigation, side-effect burden, stigma, relationship strain and the burden of varied physical symptoms. Yet our data clearly indicate that with advancing age, menopausal issues are of concern to women and pathways to care and support are needed. This may well be of greater need in areas where less provision exists. Appropriate adaptations of generalised services for women need to be included in the range of general and specific HIV services.

This study highlights the importance of considering the psychological burden of menopause and its symptoms in women with HIV, and the need for increased psychological care and support. It also highlights the very specific needs of older women

and suggests that routine documentation and enquiry of psychological state is an important part of care with associated services being made available.

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