

What problems associated with ageing are seen in a specialist service for older people living with HIV?

Shortened Title:

New multidisciplinary clinic for older people living with HIV

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Keywords: Frailty, Ageing, Depression, Cognitive impairment, Falls

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Abstract

By 2030 the majority of the people living with HIV in the United Kingdom will be over the age of 50. As a result, HIV services globally are adapting to manage people living with HIV as they age. These services are often designed based on data from the wider ageing population or from the personal experience of HIV clinicians in their own service. This article reviews the results of the first year of a specialist clinic for older people living with HIV within the existing HIV service at the Ian Charleson Day Centre, Royal Free Hospital in London, United Kingdom. It aims to help clinicians design future services to meet the most common needs of this aging population.

Keywords: Frailty, Ageing, Depression, Cognitive impairment, Falls, Sarcopenia, HIV

Practitioner Points

1. Frailty is common and can present earlier in people living with HIV.
2. Prevalent features of ageing in people living with HIV include depression, cognitive impairment, polypharmacy and falls.
3. A multidisciplinary model is successful in identifying and managing problems associated with ageing in older people living with HIV.

1. Introduction

Ageing is at the forefront of current health policy, with the United Nations branding 2020 to 2030 the 'decade of healthy ageing' (1). Conventional ageing research considers older people to be over the age of over 65, however in HIV research an age of above 50 classes you as older due to the precedent set by the United States (US) Centers for Disease Control's original age stratification of HIV/AIDS (2). Data from 2018 showed that in the United Kingdom (UK) 39% of those accessing HIV services were over the age of 50 made up of people ageing with HIV as well as those who were diagnosed at an older age and it is expected that by 2030 this will increase to 70% (3-5).

Ageing is associated with increased rates of frailty in both the general and HIV population as is, defined as 'a condition in which a person has reduced homeostatic reserves resulting in increased vulnerability to both endogenous and exogenous stressors leading to them being at increased risk of negative outcomes' (6, 7). Frailty is associated with increased rates of multi-morbidity, disability, long-term residential care placement, hospitalisation and death and can present earlier in those living with HIV (8, 9). Frailty can be assessed for and managed by undertaking what is known in Geriatric Medicine as a 'Comprehensive Geriatric Assessment' (CGA) which is a multidisciplinary assessment that covers domains including physical, psychological, functional and social abilities and has been shown to improve outcomes for older people (10).

Currently there is no gold standard model for managing people living with HIV as they age. Several models have been proposed internationally including joint HIV and Geriatric Medicine clinics such as the 'Silver Clinic' in Brighton, UK and the 'Golden Compass Programme' in San Francisco, US (11, 12). As many HIV physicians may be unfamiliar with frailty, whilst Geriatricians lack experience of HIV, joint services such as these may allow for more holistic care.

This paper explores our experience in establishing a specialist service for older people living with HIV as well as describing the main aspects of ageing with HIV identified in our cohort in the inaugural year.

2. Materials and Methods

The Ian Charleson Day Centre (ICDC) was established at the Royal Free Hospital in 1990 as the first open-access clinic for people with HIV in the UK and currently coordinates the care of 3200 people with just over half being older than 50. Many service users were presenting with problems related to ageing so a dedicated monthly multi-disciplinary clinic, 'The Sage Clinic' (non-acronymous), was formed with the aim of identifying and managing these problems.

2.1 Clinic Design

The monthly four-hour multidisciplinary clinic allowed for six patients to be seen in a carousel format made up of three 30-minute assessments, with each patient assessed for 90 minutes in total. The multidisciplinary team (MDT) was made up of the following members: HIV Physician, Geriatrician, Physiotherapist, Occupational Therapist, HIV Specialist Pharmacist and HIV Specialist Nurse. Dietetics, Speech and Language Therapy, Psychology and Social Work professionals were not available to attend and were referred onto as needed.

Prior to the clinic the referral and patients' existing medical records were reviewed to formulate a summary highlighting potential issues including possible barriers to engagement or interventions. The first of the three assessments comprised a medical review led by a Geriatrician focussing on the physical and psychological domains of the CGA (10). The assessment was performed alongside a consultant HIV Physician to provide a point of reference to the relevance of a HIV diagnosis and to ensure that there were no contraindications for any suggestions. The functional and social domains of the CGA were explored by a Physiotherapist and Occupational Therapist who reviewed mobility and function whilst providing patient education, onward referral to therapy or social services and delivery of equipment. The final part of the CGA included a medication review by a HIV Specialist Pharmacist to evaluate concordance, tolerability and drug-drug interactions. Prior to the clinic patients were sent questionnaires to ascertain information to help guide the reviews, as these were often not completed the final part of this session involved a HIV Specialist Nurse assisting with this.

At each stage attendees were provided with a summary of the professionals' findings and suggestions and were invited to ask any questions. The MDT reconvened at the end of the clinic to construct an MDT report summarising their findings, providing information on how best to support the patient that was then sent to the referring HIV clinician plus the Primary Care physician when permitted.

2.2 Patient Identification

Table 1 demonstrates the referral criteria for the Sage clinic with patients identified by their regular HIV clinician or HIV Specialist Nurse(13).

Multiple medical comorbidities (1 or more) in addition to HIV
Complex polypharmacy issues (5 or more medications excluding those to manage HIV)
Reduced/impaired mobility or reduced muscle strength
More than one fall in the previous six months
Inability to maintain activities of daily living
Underweight/ unintentional weight loss
Memory problems
Advance care planning

Table 1: Referral criteria for the Sage Clinic – One or more required.

2.3 Objective Outcome Measures

The outcome measures collected during the Sage clinic are summarised in Table 2.

Frailty Assessment	Local adapted version of the Fried Score(13) In the last 12 months have you noticed any of the following? 1. Inability to grip with hands (e.g. opening a jam jar) <input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) 2. Unexpected decrease (loss) of weight that’s worrying you <input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) 3. A slower walking pace than usual <input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) 4. Not feeling full of energy most days of the week <input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) 5. Being less or much less active compared with someone who spends 2 hours on most days on activities such as walking, gardening, household chores, or do-it-yourself projects <input type="checkbox"/> Yes (1) <input type="checkbox"/> No (0) Total Frailty score: _____
Screen for Depression	Patient Health Questionnaire-9 (PHQ-9) (15)
Screen for Anxiety	General Anxiety Disorder-7 (GAD-7) (16)
Cognitive Assessment	Montreal Cognitive Assessment (MoCA)(17)
Quality of Life Assessment	World Health Organization Quality of Life-HIV BREF (WHOQOL-HIV-BREF)(18)
Disability Assessment	World Health Organization Disability Assessment Schedule (WHODAS 2.0) (19)

Table 2: Patient reported outcome measures collected and the adapted Fried frailty criteria used by the Sage Clinic (13)

The Fried Frailty Phenotype assesses five criteria (weight loss, exhaustion, low physical activity, slowness and weakness) to determine the degree of frailty with a score of 0 indicating a person as robust, 1 to 2 as pre-frail and 3 or more as frail(13). Table 2 illustrates the adapted version used within our service using subjective questions rather than the objective measures required in traditional Fried scoring to facilitate ease of use(13).

Fried scoring is limited as it does not account for the psychological or neurocognitive aspects of frailty so depression was screened for using the PHQ-9, a nine question tool where a score of 10 or more is suggestive of depression (range 0-27)(14, 15). Anxiety was assessed for using the GAD-7 tool comprising of seven questions again where a score of 10 or more is diagnostic (range 0-21)(16). Cognitive screening was performed using the MoCA a one-page 30-point test of seven domains where a score of 26 or more is considered normal(17).

Quality of life (QOL) was assessed using the WHOQOL-HIV-BREF which comprises thirty-one questions on the patient's perceptions of their well-being over the preceding two weeks(18). Responses are given via a 1-5 Likert scale where 1 represents 'disagree' or 'not at all' and 5 represents 'completely agree' or 'extremely'(18). Questions cover six domains: physical, psychological, level of independence, social, environmental and spiritual(18). Finally, disability was assessed for using the WHODAS 2.0 a thirty-six-question tool which covers six areas: cognition, mobility, self-care, getting along, life activities and participation with a 1-5 Likert scale used with 1 representing 'none' and 5 'extreme or cannot do'(19).

2.4 Costings

HIV clinician, Pharmacist and Nursing time was provided directly from within the existing HIV departmental budget. The time of the Geriatrician, Physiotherapist and Occupational Therapist was paid for on a sessional basis, supported by an external grant.

2.5 Statistical Analysis

Data was summarised using descriptive statistics including frequency, median or with corresponding percentages or interquartile ranges.

3. Results

The records of the thirty-five attendees (nine clinics) were reviewed for demographics and the issues identified and addressed within the appointments.

3.1 Demographics

The median age of attendees was 69 years, with a preponderance of white men who have sex with men. Most patients had well-controlled chronic HIV, with 97% being virally suppressed. Full demographics including HIV markers and ART regimes are outlined in Table 3.

Clinical Characteristics (n = 35)	Results
Age: years (median; range)	69 (53 -93)
Male, n (%)	27 (77)
White ethnicity, n (%)	22 (63)
Identified sexuality, n (%)	MSM 18 (51) Heterosexual 17 (49)
Time since HIV diagnosis: years (median; range)	22 (3–37)
Duration of ART: years (median; range)	21 (3-32)
Current ART-based regimen n (%)	NRTI 29 (83) NNRTI 8 (23) PI 11 (31) INI 21 (60) CCR5 antagonist 2 (6)
HIV RNA < 40 copies/mL, n (%)	34 (97)
Nadir CD4 (cells/μL) (median; IQR)	74 (182)
Current CD4 (cells/μL) (median; IQR)	477 (319)
CD4:CD8 ratio (median; IQR)	0.8 (0.8)
Previous AIDS defining condition, n (%)	21 (60)

Table 3: Baseline demographic and clinical characteristics of persons seen in Sage Clinic

NRTI, Nucleoside/nucleotide reverse transcriptase inhibitors; NNRTI, Non-nucleoside reverse transcriptase inhibitors; PI, Protease inhibitors; INI, Integrase inhibitor; CCR5, C-C chemokine receptor type 5

3.2 Issues identified during the consultations

Eighteen discreet issues related to ageing with HIV were identified with a median of 3 per person (range 1 – 7) with the full list and frequency outlined in Table 4.

Issue	Number of Patients (n=35)	Percentage of Patients (%)
Affective Symptoms and Depression	18	51
Memory Loss	13	37
Falls	10	29
Urinary Symptoms	9	26
Pain	8	23
Weight loss	7	20
Breathlessness	5	14
Bowel Symptoms	5	14
Haematological Problems	5	14
Anxiety	4	11
Isolation and Loneliness	4	11
Alcohol Use Disorder	3	9
Modifiable Polypharmacy	3	9
Financial Insecurity	2	6
Smoking	2	6
Complications of Diabetes Mellitus	2	6
Visual Symptoms and loss	1	3
Immigration Issues	1	3

Table 4: Issues identified during assessment of patients in the Sage Clinic

Depression was the most common problem reported by over half of the sample (51%). Other common issues included memory problems (37%), falls (29%) and unexplained weight loss (20%). Polypharmacy (classified as five or more medications excluding ART) was present in 24 cases (69%) but only modifiable in 3 (9%).

Problems not directly related to ageing were also identified such as smoking, alcohol use disorder, financial insecurity and immigration issues but are relevant as these can cause physical or psychological morbidity leading to frailty.

3.3 Objective Outcome Measures

Thirty (86%) patients engaged with frailty scoring (Figure 1) with the majority (83%) being identified as frail, 10% as pre-frail and only 7% assessed as being robust (range 0-5).

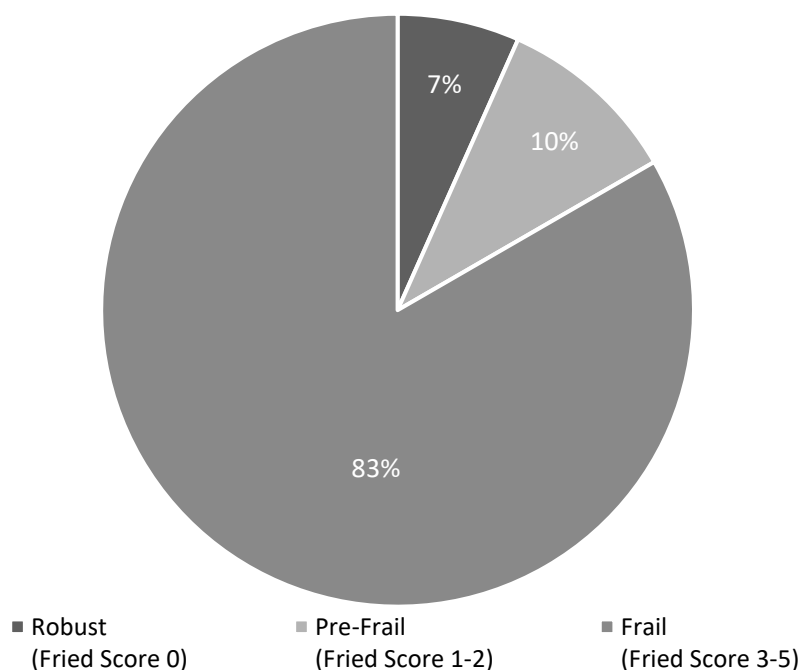


Figure 1: Distribution of Fried Frailty Scores

Thirty-one (89%) attendees completed the PHQ-9 assessment with a median score of 11 (IQR 11), and is consistent with the qualitative findings where approximately half of attendees reported feeling depressed. GAD-7 assessment was completed by thirty

(86%) patients with a median score of 6 (IQR 7) illustrating that this was less prevalent in comparison with depression and again mirroring the subjective results. Seventeen people met the criteria for depression and eight for GAD respectively.

Cognitive screening was performed for the first seven patients but was often impacted by the presence of affective symptoms which prevented engagement and patients reported they found it tiring. It often took half of the consultation with the Geriatrician to complete the MoCA resulting in less time to explore more dominant problems. The MDT discussed this unforeseen challenge and subsequently a MoCA was only completed if memory loss was a predominant symptom. A total of eight (23%) were completed with a median score of 21 (IQR 11). Six people had results suggesting cognitive impairment.

The WHOQOL-HIV-BREF was completed by thirty (86%) attendees demonstrating worse QOL across the physical, psychological, level of independence and social domains (Table 5) when compared to results from previously described cohorts(18, 20, 21). Twenty-six (74%) patients completed the WHODAS 2.0 assessment with a median score of 36 (IQR 32) approximately correlating to the 90% population percentile demonstrating a high level of disability within the cohort(19).

WHOQOL-HIV-BREF Domain	Sage Clinic Mean (SD)	Pereira et al. (2014) Mean (SD)	Meemon et al. (2016) Mean (SD)
Physical	12.34 (3.79)	13.48 (1.17)	14.48 (2.68)
Psychological	12.47 (3.05)	16.56 (1.01)	14.99 (2.48)
Level of Independence	11.15(3.75)	13.72 (1.08)	13.35 (2.39)
Social	12.77 (3.10)	13.34 (1.01)	13.32 (2.76)
Environmental	13.95 (2.81)	25.97 (0.96)	13.91 (2.21)
Spiritual	14.24 (3.67)	13.20 (1.28)	14.90 (3.42)

Table 5: Results of WHOQOL-HIV-BREF Domains in the Sage Clinic compared to previous studies (20,21)

-Pereira et al. (2014); Portugal, n = 185; mean age = 57.84 (6.79) years; mean CD4 count = 433.06 (275.65); mean years since diagnosis = 6.34 (5.20) years

-Meemon et al. (2016); Thailand, n = 329; mean age= 41.95 (7.82) years; mean CD4 count = 489.51(249.35); mean years since diagnosis = 10.40 (6.04) years

4. Discussion

All patients reported issues related to ageing with HIV regardless of their Fried score highlighting that lower frailty scores do not always equate with uncomplicated ageing. Frailty was prominent in our sample with 83% classified as frail and a further 10% as pre-frail. Our sample is small and preselected and it is likely we were referred those who were considered most symptomatic by their HIV clinicians explaining why the prevalence is so high. Though the full spectrum of Fried scores (0-5) was seen. As a result of our sampling our results cannot be extrapolated to estimate the frailty rate amongst older people living with HIV in the wider UK population. For reference the prevalence of frailty in the UK in a sample of approximately half a million people aged 37 to 73 was 3%(22). Frailty in our sample was diagnosed using a bespoke adaptation of the Fried score using exclusively self-reported information potentially limiting results. Secondary analysis of data from The Irish Longitudinal study on Ageing (TILDA) [n=4961] showed that the characteristics of frailty are similar whether solely self-reported or objective measures are used(23). With regards to people living with HIV a recent study [n=80] found similar rates of frailty when comparing an objective assessment utilising gait speed (19%) to a subjective assessment utilising a self-reported health questionnaire (20%)(24). The prevalence in our study is higher than data from an Australian study which reported 28% and results from a service for older people living with HIV in Brighton, UK which reported a prevalence of 65% (11, 15). These factors emphasise that the method of defining and identifying frailty impacts the results of prevalence.

The reported low quality of life and higher proportion of disability within our sample are similar to results found in previous studies(20, 21, 25, 26). Pereira et al. (2014) used the WHOQOL-HIV-BREF to determine the QOL in a Portuguese sample of 185 people whilst Meemon et al. (2016) did the same in a Thai sample of 329 participants(20, 21). Both samples were younger than ours; mean ages 58 and 42 respectively and also had lived with HIV for less time; 6.34 and 10.40 years which may explain our cohort scoring lower across the physical, psychological, level of independence and social domains (18, 20, 21). The United Kingdom and Portugal are high-income countries but there was a large discrepancy in the environmental domain (13.95 vs. 25.97) suggesting our cohort are less satisfied with their living conditions, comparable more to Thailand (13.91)(20, 21). This could be as our sample came from one site whilst the Portuguese sample was recruited from ten, though it may also demonstrate the impact

of older age and a prolonged time living with HIV suggesting that an earlier year of diagnosis may still be impacting a person's environment and therefore QOL(20, 21).

Socioeconomic factors such as poverty rates have been shown to directly impact rates of frailty(27). The 2017 UK national HIV patient survey, 'Positive Voices' found that financial insecurity was common with 46% of women and 32% of men with HIV living at or below the poverty line (annual household income less than £20,000), and 68% of women and 44% of men with HIV not always having enough money to meet their basic needs(28). British governmental data demonstrates higher rates of poverty, particularly in the context of older people, in urban areas such as London when compared to rural regions(29). Migrants are also more likely to be frail not fully accounted for by confounding factors highlighting the importance of enquiring about immigration issues(30). Though not highly prevalent in our cohort these factors may be contributing to our sample's frailty rate supporting that strategies for the management of frailty in older people living with HIV should be determined at the local level.

Our results also highlight the wide nature of ageing with HIV, with eighteen different issues identified. Depression was common with 51% of patients subjectively reporting affective symptoms supported by the median PHQ-9 score being 11 confirming a similar rate objectively. A high prevalence of depression in older people living with HIV has been previously reported, with a US study reporting a rate of 52% of participants [n=1000] feeling depressed within the last year(31). However, ageing alone is unlikely to be responsible for this so these results support the recommendations of the British HIV Association (BHIVA) and European AIDS Clinical Society (EACS) to screen all patients, as our service does, for affective symptoms at least annually(32, 33). Just over a third (37%) of patients in our sample reported memory problems with 63% of those who completed a MoCA [n=8] having an abnormal result. Cognitive impairment in older people living with HIV, is commonly reported when the HIV-associated neurocognitive disorders (HAND) criteria is applied(34). This shows that whilst our sample is small our results corroborate previous studies, emphasising the importance of enquiring about memory problems with services having clear local protocols for either in-house objective assessment or onward referral. Patients within our cohort with depression, anxiety or suspected cognitive impairment were managed by referrals to in-house peer support, psychology or liaison psychiatry services with a high rate of uptake by attendees.

Finally, 29% of the patients reported recurrent falls, which is similar to the findings from a US study [n=155] where 26% reported falling often(35). Falls are well reported in the Geriatric Medicine literature with evidence recommending a multidisciplinary approach combining medical review with Pharmacist led medication review and therapy led balance and strengthening exercises and appropriate walking aids(36-38). Given the complications of HIV and its treatment, knowledge of ART as well as other medication was critical and the involvement of a HIV Specialist Pharmacist was invaluable in managing this problem. Polypharmacy was prevalent in the sample (69%) but in most cases was appropriate due to the multi-morbidity associated with ageing with HIV and was not modifiable(15, 31). Cases where medications could be withdrawn predominately involved long-term use of opioids and benzodiazepines. Use of these classes of medications has been shown to be both prevalent amongst older people living with HIV and linked to increased risk of falling (11, 39, 40). Medical and Pharmacy reviews were performed alongside assessments by an experienced Physiotherapist and Occupational Therapist who could provide brief interventions and refer on to appropriate community services. Given the high prevalence of falls in older people living with HIV this supports the use of our multidisciplinary model.

People living with HIV are two-thirds more likely to be current tobacco smokers despite smoking having been shown to significantly increase the risk of frailty(41, 42). Meanwhile, the prevalence of alcohol use disorders in people living with HIV is approximately 30% with high usage associated with falls and cognitive decline, and a recent study linking chronic alcohol use to the development of frailty in people living with HIV(43-46). Despite the low prevalence of smoking and alcohol use disorder within our cohort these remain important to screen for due to their potential impact on ageing when assessing older people living with HIV.

Models of care for older people living with HIV vary worldwide. Management of ageing related problems and frailty is becoming more central to the design and delivery of HIV services with EACS emphasising the importance of frailty screening and BHIVA promoting incorporating Geriatricians into the care of complex older people living with HIV(32, 33). Similar models of care, incorporating Geriatricians into a HIV services to deliver CGA have been discussed previously, but given our location and population we have achieved almost equivalent numbers of patients through the service in a considerably shorter time as well as having greater variability in gender, race and sexual orientation which can impact the presentation of frailty(11).

Feedback from attendees was predominately positive with many happy to have had the opportunity to discuss issues not typically explored. Several highlighted the clinic being conducted within the HIV outpatient department as an incentive for them to attend as they were fearful of mainstream services due to fears of discrimination. This is not unexpected as a previous study identified anticipated or experienced stigma was a key barrier to accessing healthcare services for people living with HIV with 35% worrying that they would be treated differently, 14% having experienced discrimination and 11% having been denied or refused a treatment or procedure due to their HIV status(47). The majority felt the therapy and pharmacy reviews were useful though some reported they felt that not all areas of the assessment were relevant to them and would have preferred to self-select which to undertake. Several of the patients, primarily those with affective or cognitive symptoms, struggled with the length of the appointment and reported they would have preferred to have done them separately. The high burden of questionnaires was conveyed as a deterrent to attending.

During the COVID-19 pandemic the clinic was suspended due to staff reallocation and national recommendations to conduct appointments virtually where possible. Clinicians were advised to follow the referral procedures in place prior to the formation of the Sage clinic such as referral to local outpatient or community therapy services, though discussion of complex cases with the relevant professionals was available throughout.

After our interim analysis we have streamlined the service removing the pre-clinic questionnaires, instead allowing the selection of appropriate tools to be chosen following clinical assessment and conducted on the day. We also identify before the clinic those who would benefit from a full MDT assessment versus those require only certain reviews to prevent overwhelming attendees. Further information has been given to referrers to ensure patients are fully aware of what the clinic will entail but also to refer patients with pre-frailty also. We have recommended screening for affective symptoms prior to referral with those with high scores being referred to psychology in tandem to allow for a more meaningful patient experience. We also now offer shorter follow-up appointments to allow for the review of investigations and interventions.

To our knowledge our holistic multidisciplinary model incorporating Nursing, Therapy and Pharmacy colleagues alongside Physicians has not been previously described with regards to people living with HIV. We present these initial findings whilst we collect data around long-term outcomes and cost-effectiveness which shall be published subsequently. Despite limitations this is an evolving area with a paucity of evidence, in which this early data can contribute to the discussion of how best to deliver services to older people living with HIV(48). Our current recommendations would be that services start by ensuring they have a clear strategy in place for frailty screening to determine local prevalence, and have clear referral pathways to existing Geriatric Medicine and therapy services in place at this stage. Once local needs are established a bespoke clinic can be considered but as attendees may fear stigma or discrimination, we support welcoming external healthcare professionals into patients' existing space as the preferred model of care. We endorse an MDT approach, offering CGA with particular focus on the Geriatric Medicine syndromes of cognitive impairment, depression, falls and polypharmacy(49).

5. Conclusion

Whilst older people living with HIV are a heterogeneous group frailty is common and appears to present earlier. Our data demonstrates a high prevalence of affective and cognitive symptoms within this cohort. HIV services either need to adapt to meet these additional needs or must support users in transitioning to existing services. We feel that our multidisciplinary model of incorporating Geriatricians, HIV Physicians, Physiotherapists, Occupational Therapists, HIV Specialist Pharmacists and HIV Specialist Nurses into a single clinic is successful in identifying problems associated with ageing with HIV and, funding permitting, may be successfully replicated elsewhere depending on local clinic size, demographics and need.

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