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SHORT COMMUNICATION

How are HIV services in the UK currently identifying and managing patients with cognitive impairment? Results of a national survey

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Abstract

Objectives: The 2018 British HIV Association (BHIVA) Standards of Care state that people living with HIV should be questioned annually for symptoms of cognitive or memory decline. If symptoms are identified, screening should be considered and services offered if impairment is detected. We examined the availability of services, along with current practices related to the screening and management of cognitive impairment in people living with HIV, in UK HIV services.

Methods: A survey was distributed via email to all UK HIV services leads on the BHIVA audit mailing list. Questions related to screening practices, referral pathways, and the management of patients with suspected cognitive impairment. Descriptive analyses were conducted on all data returned.

Results: In total, 190 surveys were distributed. Of the respondents, 39 (60.6%) stated that they undertook screening for cognitive impairment in their HIV service, and 30 (47.6%) reported not offering a specific service or referral pathway. Awareness of BHIVA screening guidelines was high (49 [84.48%]), yet 15 (30.6%) respondents stated that they were not followed in their service and 41 (71.9%) felt there was a need for training on screening, assessment, and management of cognitive impairment in patients with HIV within their department.

Conclusions: Despite no directive, a substantial number of HIV services surveyed are routinely screening patients for cognitive impairment without guidance on when to screen and which screening tools should be used. A UK consensus on screening, along with guidance and training for services, may help to resolve this gap in service provision.

KEYWORDS
BHIVA guidelines, cognitive impairment, comorbidities, management, screening
INTRODUCTION

The advent of combination antiretroviral therapy has resulted in a considerable decline in the prevalence of HIV-associated dementia [1]. However, other forms of cognitive impairment remain prevalent among people living with HIV [2, 3]. As the HIV population ages, improvements in HIV diagnosis and treatment mean there exists a growing population of adults with long-term HIV who are more vulnerable to cognitive impairment than the general population [4]. Current estimates of the proportion of people living with HIV with a cognitive impairment vary according to the diagnostic criteria used, but conservative estimates suggest that between 14% and 28% of people living with HIV aged >50 years have a clinically significant cognitive impairment in the UK [3]. The 2018 Standards of Care for people living with HIV released by the British HIV Association (BHIVA) state that people living with HIV should be ‘questioned annually for symptoms of cognitive or memory decline’ [5]. Where symptoms are identified, further screening and potentially neuropsychological assessment should be offered, and if cognitive difficulties are then identified, ‘a detailed HIV-neurology review should be considered, and rehabilitation strategies/services should be offered’ [5]. The extent to which these recommendations are being carried out within UK HIV care and what service provision exists for patients who are identified through screening or otherwise remains unknown. The aim of this survey study was to determine the current availability of services, along with practices related to the screening and management of cognitive impairment in people living with HIV, in UK HIV services.

METHODS

Data were collected using the online survey platform Qualtrics (www.qualtrics.com) between April and May 2022. Survey questions were developed in collaboration with clinicians working in HIV and cognitive impairment in University Hospitals Sussex as well as with advice from BHIVA audit committee representatives. The survey was distributed to clinicians from UK HIV services on the BHIVA audit leads mailing list in April 2022, and responses were collected over 1 month. The survey (Appendix S1, supplementary file 1) included questions on current practices for screening HIV patients for cognitive impairment, referral pathways, and management of such patients within generic services or specific HIV cognitive impairment services, where they existed. Survey responses were anonymous unless the respondent chose to leave their contact details for further information.

Response rate

The survey was distributed to 190 service leads in the UK. A total of 66 responses were recorded, with 57 complete responses and nine incomplete. All responses were included in the analysis. This gives a response rate of 34.7% (66 of 190 service leads) and a completion rate of 86.4% (57 of 66 service leads).

Background characteristics of respondents

In total, 57 respondents completed the background characteristics section of the survey; 47 were based in England, seven in Scotland, one in Northern Ireland, and two in Wales. Of those, 57.9% reported ≤500 adults receiving care at their service.

HIV clinical services included standalone genitourinary HIV services (28 [49.1%]), integrated services involving infectious diseases and sexual health/genitourinary medicine departments (18 [31.6%]), infectious diseases services (4 [7.0%]), community HIV services (4 [8.8%]), and standalone HIV services (2 [3.5%]). Clinic sizes varied: 33 (57.9%) reported ≤500 adults receiving care in their service, 15 (26.3%) reported cohorts of 501–1000, four (7%) reported cohorts of 1001–2000, four (7%) reported cohorts of 2001–4000 patients, and one (1.8%) reported >4000 adults receiving HIV care at their service.

Screening and referral pathways

In total, 60.6% (40) of respondents undertook screening for cognitive impairment in their service (Figure 1). This took place during a patient’s annual health check (24 [61.5%]), during routine medical appointments (20 [51.3%]), and on an ad hoc basis (16 [41%]). In terms of the tools used for screening, 14 (37.8%) respondents said they used the European AIDS Clinical Society (EACS) screening questions [10] and 27% (10) reported using the Montreal Cognitive Assessment [8].

Overall, 28 (44.4%) respondents offered a specific service or referral pathway for cognitive impairment in people living with HIV; of those who offered screening, 57.9% (22) offered a specific service or referral pathway.
The majority described joint neurology and HIV clinics or referrals to memory assessment services or psychological/neuropsychological services.

In total, 30 (47.6%) respondents reported not offering a specific service or referral pathway for cognitive impairment, with four (6.3%) responding that they were not.
Table 1: Survey responses for questions pertaining to dedicated memory services for people with HIV presenting with cognitive impairment.

<table>
<thead>
<tr>
<th>Questions and possible answers</th>
<th>Frequency</th>
<th>Proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long has the service been running? (N = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>1–3 year</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>3–5 year</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>&gt;5 year</td>
<td>4</td>
<td>80.0</td>
</tr>
<tr>
<td>What are the entry criteria for your service? (N = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age based</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Assessment based</td>
<td>4</td>
<td>80.0</td>
</tr>
<tr>
<td>Combination of age/assessment based</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>If it is an assessment-based service, what might trigger inclusion?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Tick all that apply) (N = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening tool scores</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Neuropsychology assessment</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td>Subjective symptoms</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>What is the frequency of attendance? (N = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One-off review</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>Routine follow-up until issues resolved</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Switch of usual care to dedicated cognitive impairment service</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>Are any of the following involved in this service (tick all that</td>
<td></td>
<td></td>
</tr>
<tr>
<td>apply) (N = 4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical nurse specialist</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Clinical psychologist</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>GP with special interest</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Memory assessment service staff</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Neurologist</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Neuropsychologist</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>1</td>
<td>25.0</td>
</tr>
</tbody>
</table>

Abbreviations: GP = general practitioner;

Dedicated services

Of respondents who did not offer a specific clinic or referral pathway, 13 (44.8%) felt there was no need in their service for a dedicated memory service for people living with HIV and 13 (44.8%) were ‘unsure’. Of those stating there was no need for a dedicated HIV memory service, 12 (92.3%) cited an insufficient population, four (30.8%) highlighted barriers in funding/infrastructure, two (15.4%) cited a lack of expertise and suitable service providers, and one (7.7%) felt that there was no BHIVA guidance and that existing services managed patients sufficiently. None of the respondents felt that the evidence base for such services was lacking.

In total, five (8.1%) respondents had a dedicated memory service for people with HIV presenting with cognitive impairment (Table 1). Four services had been running for >5 years and one service had been running for 3–5 years. Only two of these respondents completed the whole questionnaire, and both were based in England. These respondents reported a variety of disciplines involved in the running of the service, including memory assessment staff, clinical nurse specialists, neuropsychologists, clinical psychologists, and neurologists.

Of the dedicated services that do exist, all respondents’ clinic were running monthly. Three of the five dedicated services offered patients routine follow-up until resolution of their issues, one clinic provided a one-off review only, and one clinic reported that patients who were referred were switched to the dedicated cognitive impairment service. The activities reportedly undertaken by dedicated services (routine or as required) varied, although all respondents responding to this question reported history from the patient, collateral history, detailed neuropsychological assessment, physical examination, review of investigations, magnetic resonance imaging, and lumbar puncture (Table 1).

Guidance and training

Awareness of BHIVA guidelines for screening for cognitive impairment was high (49 [84.48%]), although 15 (30.6%) of those aware of the guidelines reported that they were not followed within their HIV service. Of 57 respondents, 41 (71.9%) stated there was a need for training on screening, assessment, and management of cognitive impairment in patients with HIV within their department. When asked who within their department would benefit from training, 39 of 48 (81.3%) answered with some variation of ‘all staff’, ‘all clinical staff’ or ‘doctors and nurses’, and six respondents (12.5%) answered nursing staff only.
DISCUSSION

In the UK, those aged ≥50 years constitute nearly half of those living with HIV accessing services (43 584/91 432 (48%)) compared with 25% (17 499/71 253) in 2012 [11]. Given that older age is a primary risk factor for the development of cognitive impairment, and that cognitive impairment is seen at younger ages and disproportionately higher rates in people living with HIV than in the general population [12], understanding the pathways and services UK HIV clinics use to detect, diagnose, and treat cognitive impairment is of growing importance.

The survey findings indicate that screening for cognitive impairment in people living with HIV in UK HIV services is limited, with only 60.6% stating that they ask for cognitive symptoms routinely. This is despite the 2018 BHIVA Standards of Care stating that people living with HIV should be questioned annually for symptoms of cognitive impairment. Respondents reported high awareness of these guidelines, but over one-third of respondents said they were not followed within their HIV service. BHIVA monitoring guidelines neither provide recommendations regarding regular screening for cognitive symptoms nor advise which screening tools clinics should use. Despite this, over 60% of clinics are screening for cognitive impairment and with a variety of tools. The most common screening tool was the EACS cognitive impairment screening questions [10], used by 34% of respondents. The EACS recommends these questions as a simple tool to identify which patients merit formal neuropsychological testing. However, recent evidence has suggested that the positive predictive value and negative predictive value of the EACS screening questions are fairly poor (0.35 and 0.7, respectively) [13]. Given this, tools with greater sensitivity and specificity may be better placed to screen for cognitive impairment in our ageing cohorts of people living with HIV, and guidance would be beneficial.

Where cognitive impairment is suspected, 51.8% of respondents reported having no clear referral pathway. Respondents stated that patients were typically referred onward to neurology services (41.4%), generic memory assessment services (34.4%), or to their GP (31%). Studies find that patients suspected of having cognitive impairment and sign-posted to other services for assessment or investigation often struggle to remember where to go or who they are seeing and report feeling anxious about disclosing HIV status [14–16]. This results in high levels of non-attendance and creates a further barrier to care. The majority of respondents who reported no clear pathway felt that there was no need for a dedicated clinic. Given that 57.9% of respondents were from HIV services with <500 people living with HIV, this is understandable; however, a known and comprehensive care pathway for patients is required. Indeed, the causes of cognitive impairment in people living with HIV are typically multifactorial and involve complex immunopathological processes controlled by HIV factors, the direct effects of combination antiretroviral therapy, and host factors (e.g., co-infections, cardiovascular and cerebrovascular diseases, psychiatric illnesses, and lifestyle factors, including drug or alcohol abuse and social isolation) [12]. Given the aetiological complexities typically found in people living with HIV with cognitive impairment, causation, diagnosis, and management necessitate an organized, tailored, and multidisciplinary response.

The majority of respondents (71.9%) stated that there was a need for staff training on the screening, management, and assessment of cognitive impairment in people living with HIV. Indeed, there are many recommendations across the HIV and non-HIV literature supporting good cognitive health, and its promotion aligns with the 2019 UK national health service long-term plan on both ageing and prevention [17]. These include management of comorbidities, monitoring of cardiovascular disease risk, exercise, smoking cessation, and mental health support and services [18]. Taken together, these findings highlight the need for clear and consistent information detailing the processes for detecting and managing people living with HIV with, or suspected of having, cognitive impairment.

RECOMMENDATIONS

Based on the findings from this survey with HIV service leads across the UK, we recommend the following when considering the care of people living with HIV in the context of cognitive impairment.

- A UK consensus on whether case finding or screening for cognitive impairment should be endorsed, and recommendations on which screening tool is most appropriate, should be provided.
- Guidelines on referral pathways for people living with HIV with suspected cognitive impairment should be produced for clinics without a clear pathway or dedicated service.
- Training programmes on screening, assessment, pathway signposting, and management should be provided for all clinical staff working in UK HIV services.

This survey provides novel insights into the current availability of services, along with practices in screening and management of cognitive impairment in people
living with HIV within UK HIV services. Understanding how cognitive impairment is monitored, detected, and managed in services is essential if we are to understand the needs and requirements of services in the context of ageing HIV cohorts, where comorbidities such as cognitive impairment will be increasingly common. An important limitation of the study was the relatively poor response rate from HIV clinical leads (66/190 [34.7%]). Although it is difficult to ascertain why uptake was poor, possible reasons may include capacity/time constraints, questionnaire apathy, or that this is not considered to be an important issue. It would certainly be of value to gain a more representative and comprehensive view from services regarding these issues, and future research wishing to explore this further may need to incentivize services to respond. In an effort to improve response rates, we approached BHIVA, who provided us with emails of UK service leads, but we were cautious to only approach the service leads to avoid multiple responses from the same service. A second limitation was the number of completed responses who reported having a service dedicated to cognitive health for people living with HIV (n = 2). This resulted in limited information regarding how patients were managed within HIV services and our ability to base recommendations on examples of successful practice. Finally, all data were collected through self-reported methods; access to audit data would provide a clearer picture of how UK HIV services screen and manage patients with suspected cognitive impairment. Further work should consider seeking access to this data.

Overall, dedicated services for cognitive impairment in people living with HIV are extremely limited in the UK, despite an ageing HIV population and the relatively high prevalence rates of cognitive impairment seen in people living with HIV. Furthermore, despite no directive, over 60% of HIV services surveyed are routinely screening patients for cognitive impairment, suggesting that there is a clinical need to define whether those presenting with cognitive complaints in clinics are affected by cognitive impairment. A UK consensus on whether screening for cognitive impairment should be implemented is required, and, if so, guidance and training for HIV services should be developed.

AUTHOR CONTRIBUTIONS
All authors contributed to the design, data collection, analysis and writing of the manuscript.

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CONFLICT OF INTEREST STATEMENT
Rebekah Morris and Kate Alford declare no conflicts of interest. Jaime H Vera has received honoraria and research grants and been a consultant or investigator in trials sponsored by Merck, Janssen Cilag, Piramal, and Gilead sciences. He has received sponsorship to attend scientific conferences from Janssen Cilag, Gilead Sciences, and AbbVie.

DATA AVAILABILITY STATEMENT
Full data set available on request.

ETHICS STATEMENT
No ethical approvals were required for this service evaluation study.

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**SUPPORTING INFORMATION**

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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