O19 HIV and mental health: improving generic NHS talking therapy services for people living with HIV in England

Calum Douglas
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HIV and mental health
Improving generic NHS talking therapy services for people living with HIV in England
Background

• People living with HIV are disproportionately affected by mental health problems - stigma, intersectional marginalisation, trauma of diagnosis, etc

• Access to mental health support is inconsistent – some can access specialist support, but many rely on generic mental health services known as IAPT
IAPT

- IAPT (Improving Access to Psychological Therapies) is the main way the NHS provides talking therapies in England.
- IAPT services deliver NICE-approved therapies, such as CBT, to help people experiencing common mental health problems.
- Services can be accessed via referral (e.g. your GP) or self-referral, and are typically short-term.
- IAPT services are not routinely trained in HIV - concerns that they are not equipped to provide appropriate support to this population.
Methods

1. Online survey
   • 228 responses
     • 203 were eligible (adults living with HIV in England)
     • 123 had accessed therapy provided by the NHS
     • 58 had accessed IAPT

2. Interviews
   • 12 in-depth interviews reflecting key demographics
Key findings

The most common problems experienced were:

- Depression 85%
- General anxiety 55%
- Stress 47%

but significant numbers also reported:

- Panic disorder 26%
- Social anxiety 22%
- PTSD 22%

4 in 5 people reported that the problem/s were directly (19%) or somewhat (60%) related to living with HIV.

How was it related to living with HIV?

- Social stigma (being treated differently because you live with HIV) 58%
- Experience of fear of social exclusion/isolation 50%
- Long-term challenges of living/ageing with HIV 48%
- Fears about sharing HIV with others 43%
- Difficulty developing/maintaining sexual relationships 38%
- Difficulty adjusting to living with HIV 33%
- Issues with medication (e.g. side effects, adherence, etc) 33%
- Difficulty talking to others about living with HIV 33%
- Alcohol or drug use related to living with HIV 28%
- Physical impact of living with HIV (e.g. pain) 26%
- Impact of new/recent diagnosis 10%
Key findings

 Severity of mental health problems at the start and end of therapy

Start of therapy
4/5 (average 3.9)

End of therapy
3/5 (average 2.8)

Change in mental health as a result of the therapy?

- Significantly improved: 19%
- Somewhat improved: 33%
- Did not change: 39%
- Became somewhat worse: 7%
- Became significantly worse: 2%
Key findings

- A quarter (24%) of respondents felt that their HIV status negatively affected the way they were treated within IAPT.

“I felt like my therapist was keeping notes on the numbers of sexual partners I was having because she seemed to think I was spreading it around. I kept trying to explain what U=U means, but it felt like it wasn’t going in.”

Survey respondent
Recommendations

• Expert Advisory Group comprising people living with HIV, HIV support services, HIV-specialist mental health experts, mental health charities, and an IAPT course tutor.
HIV literate services

- 97%: it is important that my therapist has a good understanding of HIV
- Less than half of respondents described their therapist’s understanding of HIV as good.

Key themes:
- Frustration at having to educate others or explain themselves
- Inappropriate questions relating to risk, recklessness, and guilt
- Deterrent from seeking help or being open to receiving it

Recommendation: NHS England and Health Education England to ensure basic training on HIV, HIV stigma and ‘talking about sex’ is added to the national curriculum for all IAPT workers.
IAPT for Long-Term Conditions

• IAPT-LTC services target the mental health needs of people with LTCs
• Model brings physical and mental health providers together (e.g. via co-location) and provides IAPT staff with top-up training on LTCs
• Support for the development of HIV pathways within IAPT-LTC
• **Recommendation**: HIV to be added to the list of core conditions covered by the IAPT for Long-Term Conditions (IAPT-LTC) model…
• **Recommendation**: Specific training on the provision of psychological support to people living with HIV to be added to IAPT-LTC curriculum
• **Note**: the development of HIV pathways within IAPT-LTC is not a substitute for the commissioning of clinical psychology services in HIV services or voluntary sector HIV support services – a mixed economy is needed
Linking IAPT to wider system

- IAPT uses a stepped-care model: people are offered the least intrusive intervention appropriate for their needs first, then stepped up/down/out
- Complex needs = specialist interventions (and referral pathways) required
- Peer support – IAPT services must be aware of the value of peer support for people living with HIV, and develop pathways accordingly.

**Recommendation**: IAPT services must develop clear referral pathways with relevant services including clinical HIV services, clinical/health psychology and liaison psychiatry teams, voluntary sector HIV support services, and drug and alcohol services.
Person-centred care

- Patient choice – key principle but not evidenced in practice
- Culturally competent services – HIV affects communities that are already marginalised and disproportionately affected by mental health challenges
- Strong agreement about the importance of cultural competency (93%)
- A number of people reported their experience would have been improved by receiving support from someone of the same gender/ethnicity
- **Recommendation**: IAPT staff must be enabled to deliver culturally competent services that reflect the needs of their local populations. This should be supported by the involvement of relevant populations in the design and delivery of service…

**Recommendation**: Greater flexibility as to the types and lengths of treatment offered to patients living with HIV…
Improved data collection & reporting

- Heightened concerns around confidentiality requires better communication of how data is stored and who it is shared with.
- Sharing records with HIV clinics may be helpful/appropriate – may require review of data sharing practices.
- Increased reporting needed on the equity of outcomes from IAPT, and clear actions plans for how inequalities will be addressed.

Recommendation: Data sharing practices and policies should be made clear to patients throughout the IAPT pathway.

Recommendation: HIV should be added to the list of discrete long-term conditions that are monitored under the ‘Long term conditions’ variable in IAPT reporting.
Conclusion

• While IAPT can work for some people living with HIV, issues such as a lack of HIV literacy and poor integration with wider HIV care seriously hamper its effectiveness.

• IAPT cannot be expected to meet the diverse needs of all people living with HIV, but must be as effective as possible in supporting those who meet its criteria for support.

• Our recommendations provide clear steps for how to achieve this, and we are working with relevant decision makers to ensure they are implemented.

• This includes conversations at a national level, and our report is being used by FTC London to influence changes in local IAPT practice.
Thanks

Thank you to:

• Our project funder, Gilead
• Our fantastic Advisory Group
• All the people living with HIV who completed our survey and/or were interviewed for sharing their experiences with us
• BHIVA for hosting us today!
We’re the UK’s HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions. Our expertise, research and advocacy secure lasting change to the lives of people living with and at risk of HIV.

www.nat.org.uk

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Key findings

What type of therapy did you receive?

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>CBT</td>
<td>58%</td>
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<tr>
<td>Counseling</td>
<td>53%</td>
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<tr>
<td>Guided self-help</td>
<td>10%</td>
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<tr>
<td>Group work</td>
<td>8%</td>
</tr>
<tr>
<td>Interpersonal therapy (IPT)</td>
<td>8%</td>
</tr>
<tr>
<td>Dynamic IPT</td>
<td>4%</td>
</tr>
<tr>
<td>Sex therapy</td>
<td>2%</td>
</tr>
<tr>
<td>Eye movement desensitisation</td>
<td>2%</td>
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<tr>
<td>and reprocessing (EMDR)</td>
<td></td>
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How was it delivered?

<table>
<thead>
<tr>
<th>Delivery Method</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Phone</td>
<td>8%</td>
</tr>
<tr>
<td>Online</td>
<td>6%</td>
</tr>
<tr>
<td>Face-to-face</td>
<td>76%</td>
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<tr>
<td>Mixture</td>
<td>10%</td>
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- Waiting times:
  - Around half (52%) were seen within 8 weeks
  - A third (34%) waited more than 12 weeks
  - 1 in 10 waited more than a year
Person-centred care

Percentage of survey respondents who were given a choice in each of the following:

- The way the therapy was delivered (online, in-person, etc): 27%
- The location in which therapy was provided: 23%
- The type of therapy which was provided: 23%
- The therapist they received support from: 10%

How many sessions were offered initially?

- 6 or less: 50%
- 8 or less: 57%
- 10 or less: 65%
- 12 or less: 83%

Length of treatment

- Two thirds (66%) of respondents who completed the course of therapy they were offered reported that the length of treatment was not sufficient to meet their needs.
- Of this group, only 22% were offered further support.
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