

# Adherence: still the Achilles' heel?

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Welcome to the autumn edition of *HIV Nursing*, in which we cover 'Health promotion and adherence' as well as including the Abstracts from this year's conference.

There are interesting insights in Cathy Ormiston's article exploring the use of nurse prescribing in the field of HIV. From her research, Cathy concludes that the benefits of nurse prescribing broadly outweigh the disadvantages. However, more robust research into this skill development is needed, with an emphasis on gathering patient views and experiences.

We are pleased to hear from Liverpool's HIV Community Nursing Team on their exercise to identify gaps in care and seek improvements, in the highly challenging arena of continued care for complex patients.

Also in this edition, Pauline Jelliman reports on her work with an educative and supportive women's health initiative in the north of England. 'Between the Sheets' has received impressive initial feedback and has huge potential for developments in the future. She urges nurses, especially those in specialist roles, to pursue issues which come directly from patients – being proactive in seeking out unmet needs and creative in exploring ways to meet them.

Finally, Rachel Bath's presentation, of work trialling opt-out HIV testing across different areas within a London NHS trust, was very well received in Birmingham and is written up here. Rachel highlights some essential components for such an initiative to succeed. Before implementing HIV testing in novel settings, the testing team needs a good understanding of how a department operates, and effective communication must be established between the visiting HIV team and permanent staff in the novel setting. In order for such initiatives to be sustainable, she writes, staff must be well supported and able to take ownership of testing within their local setting.

## Time to refocus?

Part of our role as promoters of health is to offer support around treatment adherence. This topic seems to have taken rather a back seat of late – perhaps eclipsed by ground-breaking advances such as treatment as prevention (TasP) and the fervent debate about biological cure. Clearly, however, adherence to treatment remains the cornerstone of success for all strategies involving use of HAART, whether to enhance the health and wellbeing of individuals living with HIV, or as a

method of preventing infection and/or reducing onward transmission. Perhaps we need to consider whether we have become a little complacent: is it time to refocus on adherence?

The proactive, and recently renamed, International Association of Providers of AIDS Care (IAPAC) last year published a new set of evidence-based guidelines [1]. There is a shared focus, on:

- **entry into/retention in care**
- **adherence to treatment**

These two areas of care are viewed as interrelated and integral to treatment success. Recommendations in several key areas include: strategies for facilitating retention in care; monitoring adherence to HAART; and interventions to bring about improvements. The guidelines also look in some depth at the specific needs of several marginalised groups, such as: pregnant women, people with mental health concerns, those who use drugs, and the homeless – making strong recommendations for future research in these areas.

IAPAC stresses that, although the advances in pharmacology have been remarkable in this area, many people remain unable to benefit fully from them – certainly, we all continue to see many patients who struggle to take their drugs consistently. The reasons for this vary, but in the developed world may include: late diagnosis, erratic clinic attendance, mental health problems and drug tolerance issues. The importance of 'all-round success' was neatly observed: '... ultimately, both individual and public health depend on helping patients to successfully negotiate all of the steps of this treatment cascade' [2].

Summarised below are several recommendations from this IAPAC document, along with BHIVA guidance also published in 2012 [3], which I see as key to our role as nurses. There is much other material of interest and value within both these guidelines. If you have not already done so, please do take a look at them in their entirety.

## Sticking at adherence

Monitoring adherence remains a key aspect of our role, even with today's simplified regimens and improved tolerability. Monitoring effectively should identify many of those at risk of virological failure due to reduced adherence, as well as assessing the effect of interventions and guiding service and resource allocation to support those who are vulnerable. Many studies use combined measures

(such as pill counts plus self-report) to improve sensitivity and specificity, because each method has strengths and limitations. Both BHIVA and IAPAC suggest patient self-report as a user-friendly and relatively accurate method – with BHIVA indicating a preference for a series of validated questions preceded by a permissive statement [4].

Also proposed by IAPAC is the use of pharmacy refill data where appropriate. However, biological sampling, microchip electronic dispensing devices and pill counts should not be used routinely. The latter is particularly labour intensive – and in my experience often felt by patients to be a ‘policing’ approach at odds with our attempts to work in partnership and build relationships on mutual trust and respect. BHIVA stresses that the beliefs of patients about their need for ART, and any specific concerns they may have about it, should be fully explored before initiating treatment. Whilst this is established doctrine to us as HIV nurses and we have various ways of incorporating it into our practice, there are perhaps certain areas of our profession where a more research-based exploration of these issues, constructed to be consistent and systematic, could be productive.

It is also essential that this adherence assessment does not descend into tokenism or be afforded only to perceived high-risk patients, tempting as this may be in hectic, time-limited clinics. Regardless of measurement method, we really should acknowledge that adherence is a factor that varies with time and must be repeatedly assessed. Can any one of us claim to do *all* of this, *all* of the time, with *all* of our patients ... in a proactive, systematic and evidence-based way?

## Building on improvements

As we all know, considerable progress has been made in improving tolerability and pill burden – known to be important determinants of treatment adherence for many people. Several recommendations are included in both sets of guidelines to this effect. In addition, a review of the evidence concluded that some commonly used self-management adherence tools (including pillboxes and medication planners or calendars), have been associated with improved adherence and viral load suppression in some studies [5]; whereas the IAPAC guidelines fall short of making such recommendations due to a lack of evidence. On the other hand, they do advocate the use of more interactive reminders. These may include texting dose prompts, clinic appointment reminders via mobile phones, follow-up phone calls and the use of reminder prompts. However, these should only be one element of a comprehensive approach which includes education and support on a one-to-one basis. Furthermore, although group work is not ruled out, current evidence is deemed insufficient to advocate one over the other.

IAPAC states that the evidence base suggests a benefit in providing some form of discussion-based support to individuals; but that such interventions should be carefully matched to clinic populations, needs and resources. Interestingly, and surprisingly perhaps, evidence for the use of peer support apparently remains inconclusive – because most studies to date have explored it alongside other interventions and not in isolation.

## Auditing non-attendance

In contrast to the exploration of these issues in the IAPAC document, the BHIVA guidance [3] makes no substantial comment on this issue. However, an audit was very recently run by BHIVA to look at the size of this problem in the UK [6].

Together with the HPA, they used surveillance data to identify:

- patients seen for HIV care in 2010 with no linked care report from any site in 2011, and no linked death report;
- new diagnoses in 2010 with no linked care report from any site in 2010 or 2011, and no linked death report;
- [in Scotland] patients identified by clinics as seen for care in 2010, and not known to have been seen there or elsewhere in 2011.

Figures 1 and Figure 2 show the data that emerged, prompting the worrying conclusion that a possible 20% of the UK tested population was not currently accessing care.

The authors recommend that HIV services should audit non-attendance at least annually and seek to re-engage patients where necessary. Similarly, the 2013 Standards [7], at Standard 2, state that ‘services must have mechanisms in place for those who miss appointments or transfer their care to another centre, to ensure people with HIV are retained in specialist care’.

## Taking the lead

The Abstracts are included within the editorial content, and we hope that members find it useful to have this permanent record of the wide range of activities that NHIVNA colleagues are involved in, and routinely contribute to our annual event. An impressive total of 43 Abstracts were accepted this year and all were of a high quality, with the current issue theme being well represented. Several presentations looked at rolling out HIV testing. The diversity of patient experience in this context – for example, of fathers, teenagers and women – and meeting the needs of these groups, were important areas of practice addressed by several authors and speakers.

Nurses are clearly thinking about the impact of many factors on regular clinic attendance, and making inroads towards addressing some of these.

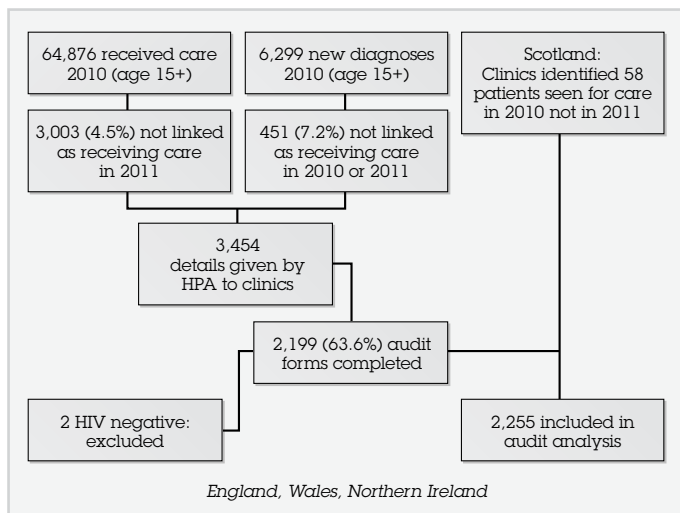


Figure 1: British HIV Association (BHIVA) audit outcomes [6], slide 4

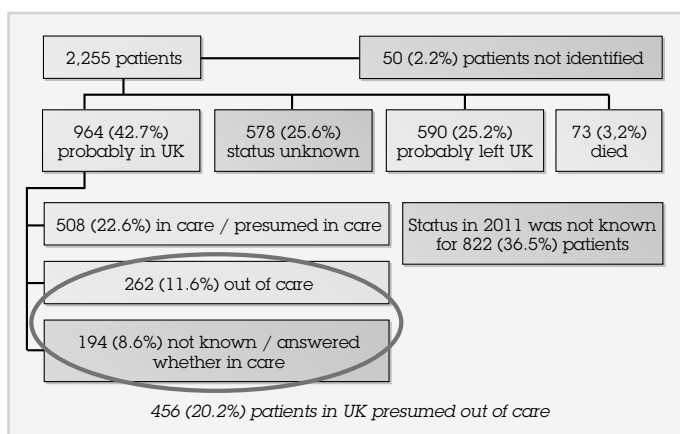


Figure 2: British HIV Association (BHIVA) audit outcomes [6], slide 7

One example was Poster abstract P8 which discussed the implications for those who disengage from treatment due to beliefs inconsistent with conventional medical knowledge. In addition, Poster abstract P27 explored the impact of faith-based healing and cure claims, which heighten risk of patients being lost to follow-up.

Other innovations presented, such as virtual clinics, integrated care pathways, improvements in communication, and normalising HIV testing, should also make a difference – but the clear need remains for all these initiatives to be properly evaluated. This presents an opportunity for all nurses to take the lead in developing local strategies to explore and address the issue of retention in care.

Please do share your ideas and practices with other NHVNA members via our website, on this important element of care provision.

## References

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