How does specialist nursing contribute to HIV service delivery across England?

PIERCY, Hilary <http://orcid.org/0000-0002-7663-8858>, BELL, Gill, HUGHES, Charlie, NAYLOR, Simone and BOWMAN, Christine

Original research article

INTERNATIONAL JOURNAL OF STD & AIDS

International Journal of STD & AIDS
2017, Vol. 28(8) 808–813

DOI: 10.1177/0956462416672128
journals.sagepub.com/home/std
SAGE

How does specialist nursing contribute to HIV service delivery across England?

Hilary Piercy[1], Gill Bell[2], Charlie Hughes[2], Simone Naylor[2] and Christine A Bowman[2]

Abstract

This study aimed to examine what specialist nursing contributes to HIV service delivery across England and how it could be optimised. A three part multi-method qualitative study was undertaken, involving (1) interviews with 19 stakeholders representing professional or service user groups; (2) interviews with nurse/physician pairs from 21 HIV services; and (3) case studies involving site visits to five services. A framework analysis approach was used to manage and analyse the data. There was substantial variability in specialist nursing roles and the extent of role development. Most hospital-based HIV nurses (13/19) were running nurse-led clinics, primarily for stable patients with almost half (6/13) also managing more complex patients. Role development was supported by non-medical prescribing, a robust governance framework and appropriate workload allocation. The availability and organisation of community HIV nursing provision determined how services supported vulnerable patients to keep them engaged in care. Four service models were identified. The study showed that there is scope for providing a greater proportion of routine care through nurse-led clinics. HIV community nursing can influence health outcomes for vulnerable patients, but provision is variable. With limited financial resources, services may need to decide how to deploy their specialist nurses for best effect.

Keywords

HIV care, HIV nursing, service development, specialist nursing, community care

Date received: 18 May 2016; accepted: 23 August 2016

Introduction

HIV infection is now a long-term medical condition. Care is focused on managing antiretroviral therapy and HIV-associated co-morbidities.[1,2] Care costs are escalating as both patient numbers and the proportion taking medication increase.[3]

Changes to funding have arisen from the separation of commissioning of HIV services from HIV prevention and sexual health services[4] and the introduction of Payment by Results for HIV care linked to different levels of complexity and associated care costs.[5]

There is an urgent need to review and develop existing models of HIV service delivery to address changing health requirements within the context of increasing financial constraints.[6–8]

The HIV and AIDS UK Select Committee recommendations included developing the specialist nursing contribution to HIV care.[8] A recent scoping review identified substantial variability in HIV specialist roles across the UK and a lack of information about role effectiveness in the international literature with a particular paucity of information from a UK context.[9]

This study aimed to examine what specialist nursing contributes to HIV service delivery across England and how to optimise this.

Methods

A multi-method qualitative, sequential approach involving three stages was used. Sampling, data collection and analysis processes for each stage were informed by the preceding stages. Data were collected between April 2014 and May 2015.

[1]Centre for Health and Social Care Research, Sheffield Hallam University, Sheffield, UK
[2]Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Corresponding author:
Hilary Piercy, Centre for Health and Social Care Research, Sheffield Hallam University, Sheffield, UK.
Email: h.piercy@shu.ac.uk

Stage 1

This stage included semi-structured interviews with a purposive sample of senior and experienced individuals, including representatives from national HIV organisations. Interviews explored current provision, challenges and opportunities for service delivery and advanced nursing contributions from multiple perspectives.

Stage 2

This stage included semi-structured interviews with nurse/physician pairs from HIV services across England to understand the different approaches and nursing contributions. Purposive sampling ensured variability in terms of demographic factors and types of HIV service. Sites recognised for excellent and innovative nursing practice were included.

Stage 3

This stage included five detailed case studies of stage 2 sites selected to capture the range of specialist nursing roles across different settings. Data collection during site visits involved semi-structured interviews, non-participant observation and service documentation.

Interviews were conducted by telephone or face-to-face in work settings and guided by a schedule designed for the specific project stage. Average time was 40 min (range 15–70 min). All were recorded and fully transcribed. All participants gave informed consent.

Data were analysed using framework analysis.[10] This structured approach contributes to transparency and validity of results while allowing the integration of predetermined and emerging themes. Analysis was undertaken collaboratively by the project team. To ensure rigour, interviews were coded by two researchers and key analytic decisions including development of the thematic framework were agreed collectively.

Ethical approval was secured from Sheffield Hallam University Faculty Ethics Committee (ref 2013-4/HWB/HSC/STAFF/9). Research Governance approval was obtained from all study sites.

Key findings

Overview of participants

Stage 1 involved 19 semi-structured interviews with representatives from five key stakeholder groups (see Table 1).

Table 1. Stage 1 participants.

Stakeholder group	Participants
Service users (2–20 years' experience of HIV services)	4
Senior medical consultants	8
Senior nurses	5
HIV network managers	1
Service commissioners	1

In stage 2, 44 semi-structured interviews were conducted with 22 nurses (N) and 22 physicians (P) working in 21 services (13% of total in England). In 19 services, we conducted two interviews and in two services where the role was differently configured, we conducted three interviews. The sample covered seven high and 14 low HIV prevalence areas: six semi-rural, 11 urban and four metropolitan locations. We included four standalone HIV services, 14 located in Sexual Health/GUM services and two in Infectious Diseases units. The HIV cohort size ranged from 80 to 6000. The majority of services (13/21) employed one or two specialist nurses. Most nurse participants (19/22) were employed to work in hospital-based services, with three employed to work in the community.

Stage 3 case studies focused on three hospital and two community-based specialist nurses from high (3) and low (2) prevalence areas.

An overview of nursing roles

A wide range of HIV specialist nursing roles was identified. Those located within HIV services were primarily hospital based and worked with the whole cohort in contrast to those located in community services who worked with HIV services to support a sub-cohort of patients with complex psychosocial and/or physical care needs.

The degree of role development also varied considerably (Figure 1). Most commonly, developments related to extending clinical skills. In some services, nurses were in leadership roles and making substantial contributions to service development and improvement. In a minority of services, nursing roles were largely undeveloped.

Developing nurse-led clinics

Nurse-led clinics were well established in approximately two-thirds of the study sites where they delivered a substantial proportion of patient care primarily for medically stable patients. The main drivers for development were capacity demand and financial constraints related to the new tariff.

Nurse-led clinic activities included new patient assessments and routine review of stable patients as well as adherence support, psychosocial care, sexual health screening and health promotion activities. Several clinicians suggested that these comprehensive holistic consultations had contributed to service

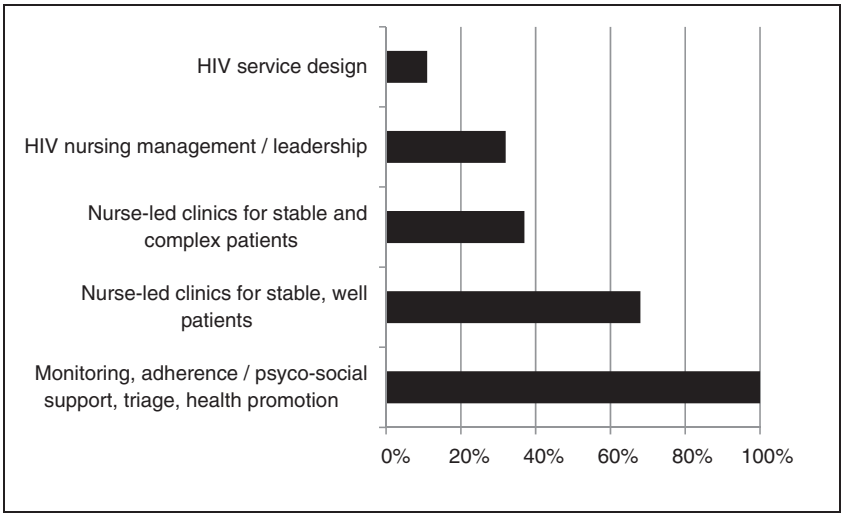

Figure 1. Role development of hospital-based HIV specialist nurses.

efficiency and acceptability. One said their nurse-led clinic had 'definitely improved the patient experience, there's more flexibility for the patients' (P2) and another that 'they [the specialist nurses] are more of a one-stop shop . . . everything at one time so more holistic and convenient' (P7).

The majority of nurses running nurse-led clinics (12/13) were qualified as prescribers and, as a minimum, routinely issued repeat prescriptions for antiretroviral drugs and a limited range of other treatments. Supporting specialist nurses to undertake a prescribing qualification was regarded as highly beneficial for services enabling clinics to run smoothly and efficiently. The mentorship requirement of the non-medical prescribing programme provided a framework for formalised clinical supervision including regular meetings between nurse and consultant HIV physician. This prescribing qualification also increased access to services through nurse-led out-of-hours provision, satellite clinics and virtual clinics.

In some services, nurse prescribers were taking more advanced treatment decisions 'managing patients who are on and off treatment, starting new regimes and changing regimes' (N 3). Robust clinical governance structures including multidisciplinary medication reviews and treatment algorithms supported this process and ensured safe practice. They were also dealing with greater medical complexity. Sometimes this had happened by default because 'anything ends up coming into [the nurse-led clinic]' (N 15). Other services had taken a planned approach including additional training in clinical assessment and on-going clinical supervision to enable the nurses to run triage clinics and manage their own patient caseloads as one explained:

> I manage a mixed caseload of approximately 300 patients consisting of 70% clinically stable who require routine six monthly follow-up and 30% who are clinically unstable, either not taking treatment or not taking it well; and who need more frequent follow up for psychosocial support. (N 6)

In some services, the amount of time specialist nurses spent acting as 'a secretary, a receptionist, a healthcare support worker' (N 11) served as a barrier to role development. A skill mix review undertaken in one service found that the nursing team were spending 50% of their time on activities that could more appropriately be done by someone else. Restructuring the team to include administrative and support workers had enabled them to introduce several service developments including establishing nurse-led clinics.

Supporting re-engagement in care

The second key aspect of the role was to provide targeted care and psychosocial support for those with complex needs and at risk of disengaging from treatment. The extent and approach to this work varied substantially between services. A key determining factor was the availability and organisation of community HIV nursing provision. Four different models were identified (Figure 2).

Model one. In these services, all re-engagement work was necessarily undertaken from the hospital. In some, it largely consisted of trying to maintain direct contact by telephone or letter with those whose non-attendance triggered concerns about disengagement. Other services had identified high levels of need and directed a substantial amount of nursing resource towards 'certain patients that need more intensive care

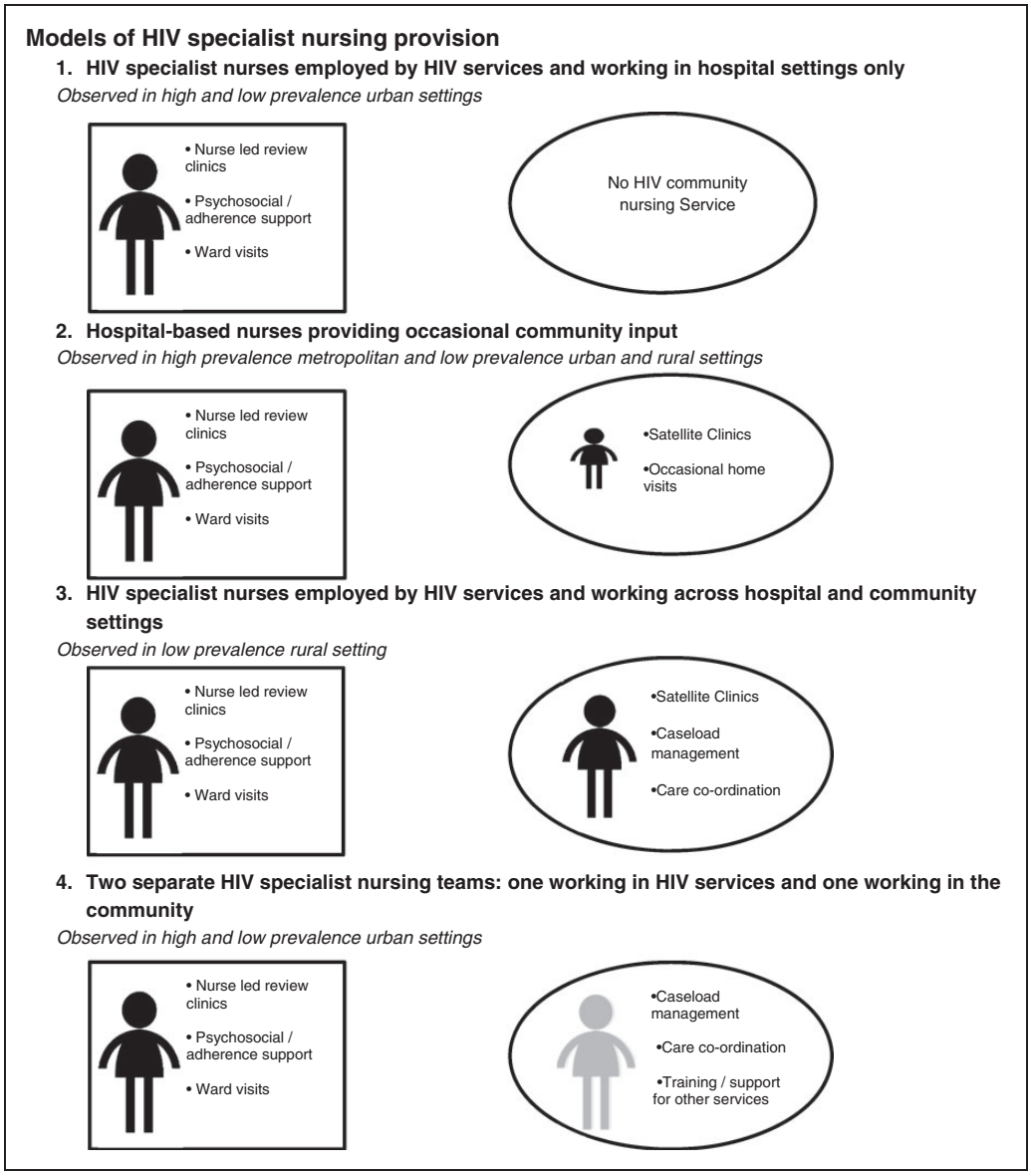

Figure 2. Models of HIV specialist nursing provision.

and support' (N 2). They had developed nurse-led initiatives with systems for identifying patients with complex problems and then 'trying to work with them . . . build up relationships with keyworkers, drug workers, . . . outside agencies to try and work together to try and bring this person in' (N 9).

Their ability to re-engage patients was very limited as one nurse explained: 'we're trying to re-engage people in care that haven't been [attending] . . . we need a community outreach team . . . to be able to go out . . . , re-engage them back into care and support them through those difficult times' (N 2).

Model two. This operated in most low prevalence areas. Limited community provision delivered services to patients in institutional care including prison and exceptionally provided home-based care, for example where 'the only way we could get him to re-engage actively would be by calling on him at home' (N 20) or for 'people who are sick at home who need to be visited' (P 1). Participants were clear of the value of this provision. One physician explained 'it's a high labour input [but for] . . . those sort of patients, they are absolutely essential . . . they're critical' (P 1).

Model three. This was seen in two low prevalence areas where the role explicitly spanned hospital and community settings. They managed a caseload of patients and delivered care across all settings including supporting inpatient care, delivering satellite outpatient clinics and

undertaking home visits. Their community perspective offered specific benefits because they had detailed insights into the needs of their patients and were able to work pro-actively to keep those patients engaged with treatment. Physicians identified the benefits of this approach in providing 'intensive support' for 'those that are just on the edges of services and would be easily lost to them if there wasn't someone out there advocating', who without that support would 'probably just be left floundering, deteriorating and getting ill' (P 10). Strong links with secondary and primary care enabled these nurses to co-ordinate discharge planning because they were well positioned to ensure integrated care. This reduced hospital stays and the likelihood of readmission because they addressed the 'big problems that severely impinges on the patients and can be a real hold up to discharge' ensuring that 'things get done properly and quicker' (P 10).

Model four. Where separate hospital and community-based nursing teams existed, the community nurses worked with caseloads of patients with multiple psychosocial problems and highly complex needs. They provided input that would not be possible in other service models, for example community-based early interventions for patients when escalating drug problems put them at high risk of disengagement or advocating with services to facilitate access and appropriate care. They also had a care co-ordinator role working across agencies to establish packages of care, as one physician explained:

> [The community HIV nurse] keeps these people engaged . . . works with them to [prioritise issues] . . . engage with clinicians to make sure things are done in a co-ordinated way and no one's doing everything twice . . . There are patients who I could not manage without her . . . Wherever I've worked before, where these services did not exist . . . these patients largely died quite quickly. (P 5)

Discussion

This is the first study to examine how specialist nurses are contributing to HIV care and how their roles have developed in services across England. Our purposive sampling approach and sample size enabled us to examine roles across a wide range of services and settings. Given the degree of variability, some roles may not have been adequately captured; however, the size of the sample strengthens the applicability of our findings.

Developing the specialist nursing workforce to deliver an increasing proportion of HIV care has enabled some services to meet growing capacity demands and to improve access. This is supported by the literature that indicates comparable clinical outcomes and patient satisfaction for nurse and physician delivered care.[11,12] There is scope for further development: a recent survey of sexual health services across the UK reported that only 47% of those providing HIV services offered nurse-led clinics.[13]

Hutchinson et al.[6] acknowledged the need for HIV services to move towards community-delivered care. One model of shared care for stable patients involves GPs providing routine care with specialist services overseeing antiretroviral therapy. However, this may only be appropriate in GP practices with a special interest in HIV and a sufficient HIV caseload to acquire and maintain clinical expertise. An alternative model involves HIV specialist nurses delivering care in satellite settings and through virtual clinics. This may have greater applicability across high and low prevalence areas. It could also facilitate multi-step patient pathways involving medical as well as nursing input for more complex patients.

Community-delivered specialist nursing care as provided in models three and four is resource intensive but services with this provision were convinced of its value improving health outcomes for the most vulnerable. The available evidence indicates it reduces hospital admissions and shortens hospital stays[14] with potential cost benefits. A more detailed assessment of cost effectiveness is required to inform commissioning decisions. Contacting patients from a hospital base to try and re-engage them in care appears to have limited success[15] and services may therefore benefit from combining hospital and community nursing roles. This could provide continuity of care across settings and better enable vulnerable patients to stay engaged with care. It could also contribute to development of a more integrated chronic disease shared care model between primary and secondary care which is increasingly important in terms of an aging cohort and multiple morbidities.[6] Such models depend on good communication, partnership working and adequately trained staff in order to function effectively.[7] Specialist nurses with a community remit could facilitate this, with a bridging role between primary and secondary care services.

With limited financial resources, services may need to make difficult decisions about how to deploy their specialist nurses for best effect. Should they prioritise roles managing large numbers of patients or those focused on improving health outcomes for the minority at high risk of disengagement from care given the impact on onward transmission, treatment failure, illness and hospitalisation? Our study shows that specialist nurses make substantial contributions to both aspects of care and supports a balance of investment in both roles.

Authors' contributions

HP and CB conceived and designed the project. All authors were involved in all stages of the project and contributed to the paper.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by an unrestricted education grant from ViiV Healthcare Ltd, UK

References

1. McManus H, O'Connor CC, Boyd M, et al. Long-term survival in HIV positive patients with up to 15 years of antiretroviral therapy. *PLoS One* 2012; 7: e48839.
2. Rodriguez-Penney A, Iudicello J, Riggs P, et al. Co-morbidities in persons infected with HIV: increased burden with older age and negative effects on health-related quality of life. *AIDS Patient Care STDs* 2013; 27: 5–16.
3. Skingsley A, Kirwan P, Yin Z, et al. *HIV new diagnoses, treatment and care in the UK 2015 report: data to end 2014*. London: Public Health England, 2015.
4. Public Health England. Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV. Part 1: Main guide, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214924/HIV-Outpatients-A-Simple-Guide.pdf. (2015, accessed 7 July 2016).
5. Department of Health. HIV outpatient and payment by results currency – a simple guide, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214924/HIV-Outpatients-A-Simple-Guide.pdf (accessed 7 July 2016).
6. Hutchinson J, Sutcliffe LJ, Williams AJ, et al. Developing new models of shared primary and specialist HIV care in the UK: a survey of current practice. *Int J STD AIDS* 2016; 27: 617–624.
7. Mapp F, Hutchinson J and Estcourt C. A systematic review of contemporary models of shared HIV care and HIV in primary care in high-income settings. *Int J STD AIDS* 2015; 26: 991–997.
8. House of Lords. Select Committee on HIV and AIDS in the United Kingdom. First report: No vaccine, no cure. HIV and AIDS in the United Kingdom, 2011.
9. Tunnicliff SA, Piercy H, Bowman CA, et al. The contribution of the HIV specialist nurse to HIV care: a scoping review. *J Clin Nurs* 2013; 22: 3349–3360.
10. Spencer L, Ritchie J, O'Connor W, et al. Analysis in practice. In: Ritchie J, Lewis J, McNaughton Nicholls C, et al (eds) *Qualitative research Practice*, 2nd ed. Thousand Oaks: Sage, 2014, pp.295–346.
11. Wilson IB, Landon BE, Hirschhorn LR, et al. Quality of HIV care provided by nurse practitioners, physician assistants, and physicians. *Ann Intern Med* 2005; 143: 729–736.
12. Hekkink CF, Wigersma L, Joris Yzermans C, et al. HIV nursing consultants: patients' preferences and experiences about the quality of care. *J Clin Nurs* 2005; 14: 327–333.
13. Wiggins H, Kell P, Joshi U, et al. A national survey of nurse-led and delivered services within sexual health across the United Kingdom. *Int J STD AIDS* 2015. Epub online first 1 October. DOI: 0956462415609001.
14. Harris J. North West HIV and AIDS Monitoring Unit. Public Health Institute, Liverpool John Moores University, 2014.
15. Cullen BL, Codere G, Wallace LA, et al. British Association for Sexual Health and HIV Scottish investigation 2010–2011: reasons for non-attendance in individuals lost to follow-up for HIV care for more than 12 months in Scotland. *Int J STD AIDS* 2013; 24: 481–484.