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HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Nurse-led practice

Editorial

Features

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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Evolving issues in the provision of HIV care today and in the future: how can HIV nurses impact on these?

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North East London HIV and Sexual Health Network Coordinator

In 2006 HIV celebrated its 25th birthday and as is true of us all, with the advancing of years our personality alters! However, far from mellowing with age, HIV has become increasingly complex. We face major clinical challenges in its pathology, side-effects, evolution and emerging technologies. Additionally, there remain major social challenges in its demography, ongoing stigma, entitlement to care and the far-stretching implications of living longer with HIV.

Figure 1 highlights some of the key issues inherent in the provision of HIV care today and in the future and it is perhaps fitting at the start of the year to consider these and the nurse's impact on them.

Political issues influence all aspects of HIV care provision. We are now working within an increasingly cash-conscious NHS. Payment by Results and set tariffs for patient care and treatment mean that the financial cost of HIV provision will increasingly dictate the choices and range of services offered to patients.

Nurses' impact on provision will be in their ability to work creatively and flexibly within the financial constraints of the NHS. This may necessitate making tough decisions around how and how frequently clinics are held or bloods taken. It also means that as members of the multi-disciplinary team we can no longer shy away from sensitively explaining to patients the cost implication of certain initiatives. Some initiatives, for example the home drug delivery scheme, have the potential to make financial savings that can be put back into service delivery for patient benefit. Furthermore it means that we will need to work collaboratively with existing patient forums to establish new channels of communication with patients so that they understand the implications of some of these policies on providing care.

As a specialty we are also in the midst of a major review of how services are provided both nationally, with the publication of the *Standards for HIV Clinical Care* [1], and locally. There is a movement away from reliance on tertiary towards primary care provision and a distinction in the types of HIV specialist services. The establishment of geographical networks are advocated as the mechanism through which equity in access, care standards and treatment is ensured. The impact of the nurse, through working with the multi-disciplinary team to establish effective patient care pathways and in liaison with primary care and other service providers, cannot be underestimated.

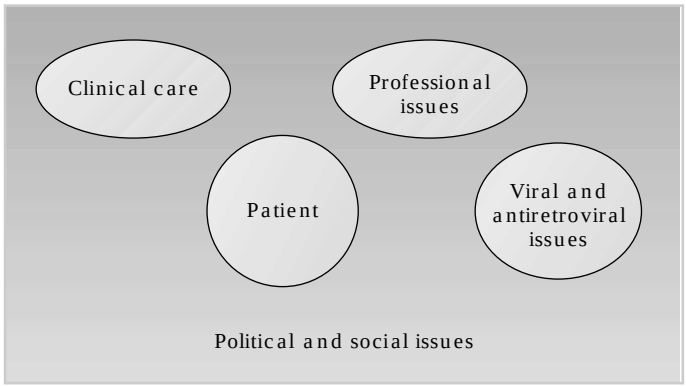

Figure 1: *Evolving issues in the provision of HIV care today and in the future.*

Additionally, 2006 saw far-reaching legislative changes in eligibility to care, dispersal and the criminalisation of HIV-positive persons for knowingly transmitting the virus.

HIV nurses have historically evolved within the multi-disciplinary team as powerful patient advocates. They now sit however, within a multi-disciplinary team that consists of many powerful patient advocates. Within today's current political legislative climate, the impact of nurses as secure confidants to the patient cannot be underestimated. Furthermore, it has become even more critical as we care for an increasingly disparate and dispersed patient population that trusting therapeutic relationships are developed and maintained.

We are also facing a plethora of clinical care issues in HIV provision that include:

- Increase in numbers of HIV-positive persons;
- Changing demography;
- Sex, sexually transmitted infections (STIs) and superinfection;
- Conception and contraception;
- HIV-infected children becoming adolescents and adults;
- Employment;
- Co-infection and co-morbidities;
- Mental health;
- Death.

Nurses may impact on these either directly through their interactions with patients or indirectly through other healthcare professionals.

It is likely that the current trend for nurse-led clinics will continue into the future. Critical to the level of impact that these clinics can have on patient empowerment is that nurses maintain and update their knowledge and skills to reflect the changing personality of HIV. Nurses will increasingly be the first or only contact that the patient has during a clinic visit. The newly diagnosed will continue to require sensitive HIV-related information and as more patients live stably with their HIV, on or off antiretroviral therapy, nurse-led clinics will have their greatest impact through encompassing a 'one-stop shop' model. This would mean that patients can, in one visit, receive specialist information and education but also broader more general health information or screening that enables them to make better decisions related to their health.

Nurses can additionally have an impact on clinical care issues through their interaction with other healthcare professionals and ensuring the patient pathway is a seamless one. Collaboration, close working, sharing and imparting of specialist HIV or antiretroviral knowledge with professionals working in primary care and non-statutory organisations will become increasingly important as patients live longer and come into contact with a wider variety of professionals.

Implicit in all clinical care is the need for audit and clinical governance to maintain high quality. Again the nurse has a central role to play both in the conducting of clinical audit and implementation of the findings.

Viral and anti-viral challenges represent a major challenge today and for the future in HIV care provision, particularly with increasing drug resistance. Drug resistance may be present at diagnosis or as a consequence of sub-therapeutic regimens, poor adherence or simply years of living with HIV. The need for, and access to, new drugs that are able to maintain immune status will become increasingly important as will the challenge of poly-pharmacy as our patients become older or affected with co-morbidities or infections.

Over the course of the last quarter of a century we have learnt a lot about the virus but our understanding of the implications of prolonged immune suppression for the body is continuing to emerge as is our understanding of some of the long-term consequences of being on antiretroviral therapy. Adherence or treatment support clinics will continue to be a major part of how the nurse impacts on care provision and shapes the patients' experience of their virus. Nurses will need to be committed to continually updating their knowledge of drugs and drug interactions, side-effects and their management and resistance pathways. Also, as the demographics of our patients changes, nurses will need to adapt the way treatment support is offered so that it is culturally and age sensitive. And finally, the nurse can both formally and informally impact on who, how and where viral and antiretroviral information is given through educating those that have patient contact.

The last key challenge is one that relates to healthcare professionals themselves. Decreased numbers of newly qualified nurses, Agenda for Change, opening of the formulary for nurse prescribing, nurse consultants and changes in the way that our medical colleagues practise each present opportunities for nurses to shape HIV care provision. Nurses may also influence who cares in the future by encouraging newly qualified nurses to the specialty either within their own areas of work or to outside audiences at conferences.

As HIV enters its 26th year there are undoubted challenges ahead. HIV continues to be a complex condition and our knowledge of the true implications of living longer with a compromised immune system is evolving. Whilst the issues highlighted may develop or be replaced by new challenges, the patient will remain at the centre of care provision. The nurse's greatest impact will therefore be in coordinating the patient's experience of care and providing continuity within a rapidly changing and evolving NHS and HIV world.

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Nurse-led care in HIV: opportunities and threats

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What are nurse-led services aiming to achieve?

Recent health policy, for example *Making a Difference* [1], *The NHS Plan* [2] and *The National Strategy for Health and HIV* [3], all advocate challenging traditional healthcare roles and professional boundaries and expanding the role of the nurse. At first glance this looks like a great opportunity. However it is important to be aware of the drivers behind this development, and the potential threats to our role as nurses and to patient care, as well as the opportunities for positive outcomes.

Increasing pressures to improve quality and patient choice, reduce waiting lists, reduce or maintain costs and enhance the status of non-medical professionals have all had a powerful impact on ways of working. Today's NHS needs to rebalance an escalating workforce–demand mismatch and nurse-led care can be seen to arise from these changing dynamics as a potential strategic option and alternative model of care.

HIV care has always been shaped by patient need, and HIV nursing in the 1980s and 1990s was at the forefront of innovation. 'On virgin territory and fully resourced, we had the opportunity to implement real, patient-centred holistic nursing care,' recalls Bruton [4]. However times have changed and today there is always the risk that roles may alter primarily as a result of the pressures mentioned above. It is therefore imperative that as nurses we have our patients' interests at the heart of any new development. We must not lose sight of the core of the nurse's role. Improving our already high standards of holistic care and patient satisfaction must always be our main motivation for change. It is our job to ensure that this is, and continues to be, the patient's experience of our interventions.

What is nurse-led care?

Despite the widespread use of the term, there is no agreed definition of nurse-led care. The danger of working without a concrete understanding of what these new roles entail, may leave us at risk of losing our sense of direction or purpose, or even our very identity, as providers of holistic care.

We could take the term to mean services that are principally managed and run by nurses. However, Richardson and Cunliffe *et al.* [5] report that the perceptions of nurses of what this entails in practice varies significantly, from task-orientated substitutions of nurse for doctor carrying out single medical tasks, to the autonomous management and care of a total patient 'episode'.

Briggs [6] offers us some guidance by summarising the common features of nurse-led care, which gives us a basic template by which to evaluate our scope of practice, both current and in our envisaged future.

- A direct referral mechanism.
- Clinical assessment and technical skills.
- Freedom to initiate diagnostic tests.
- Prescription of medications.
- Increased autonomy and scope for decision-making.
- Responsibility for discharge from the service.

However, it may be easier to view nurse-led care on a continuum (Figure 1), and this would align more readily with the NHIVNA Competency framework [7].

Opportunities in HIV care

There are numerous factors in HIV care that might make 'nurse-led care' a particularly appropriate model to meet the needs of service users.

- HIV nursing has a reputation for innovation and a willingness to change and adapt to new challenges and circumstances.
- HIV-positive patient groups have historically made their needs known, demanded choice and have been keen to evaluate service provision. Patients are vocal and knowledgeable and prepared to challenge the 'status quo'.
- HIV care has a reputation for effective multidisciplinary team collaboration.
- Nurse-led care may be particularly relevant in the management of clinically stable patients, leaving specialist medical staff to focus on the acutely ill, interpretation of specialist results and antiretroviral treatment changes, etc.
- Nurse-led care is also very appropriate in the palliative stage of HIV care, where nursing expertise in providing comfort, dignity, emotional support and symptom alleviation are chief components of care.

Very few HIV-specific nurse-led initiatives have been published to date. Those that have been are largely related to adherence and one describes a therapeutic drug monitoring service [8]. Whilst

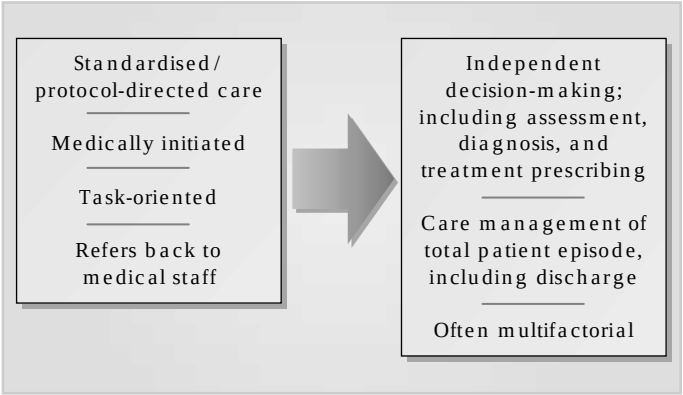

Figure 1: *The continuum of nurse-led care.*

holistic in their approaches, none appears to account for a total and multifaceted patient 'episode'.

The management of clinically stable patients who are taking HAART is a possible role for HIV specialist nurses and meets the criteria suggested by Briggs, mentioned earlier. Within this intervention there would be considerable emphasis on psychosocial care, for example the exploration of adherence difficulties, mental health assessment and sexual health, as well as monitoring clinical outcomes and management of regimen-induced side-effects. Walk-in services, with nurses triaging those experiencing difficulties with HAART regimens or possible HIV-related infections, and the subsequent management of patients who meet specified criteria is another possibility. Assessment, planning for and the administration of facial fillers for lipoatrophy and HIV testing with new 'well' positive patient follow-up clinics are also potential opportunities for nurses to lead care provision.

A study by Harris and Taylor [9] found that training as independent prescribers and in clinical assessment and diagnosis can increase a nurse's sense of satisfaction because of the ability to provide more effective, timely and comprehensive care for their patients. This increased autonomy can improve continuity of care and enhance choice and ease of access for patients. With the right resources and skills these are exciting opportunities for suitably competent nurses.

Potential threats

- A return to task-orientation.
- Nurses being seen as 'mini doctors', and loss of nursing identity.
- Loss of emphasis on holistic care.
- Cultural/historical resistance to change from all professions, including nurses themselves.
- Breakdown of working relationships with doctors as a result of resistance and/or a combative approach to implementing change.
- Reduced time for psychosocial support including treatment adherence support.
- Risk of litigation.

Several authors, for example Castledine [10] and Bruton [4], advocate caution in such role developments. If we allow the development of nurse-led services in order to substitute for medical staff and/or for cost reduction we risk a significant reduction in effectiveness in the provision of the basic and essential holistic care that is the very essence of nursing. We also risk increased patient dissatisfaction, complaints and potential litigation. Possible threats include:

Significant resistance to change has been very apparent from some quarters and is demonstrated by the comments of the Chairman of the BMA's Consultants Committee [11] when he referred to the development of nurse prescribing: 'This is an irresponsible and dangerous move. Patients will suffer. I would not have me or my family subject to anything other than the highest level of care and prescribing, which is that provided by a fully trained doctor.'

Clearly, nurses will need to use all their knowledge of change management, their diplomacy and resilience to bring about this significant cultural shift. It may only be with time that we are able to demonstrate our value and efficacy in these new roles, to those who are resistant and cynical.

Chapple *et al.* [12] remind us of the importance of patient perception and acceptance if nurse-led initiatives are to be successful. Continuity of care and continued psychosocial support was also identified in this study as the basis for high levels of patient satisfaction. When we take up these new and exciting opportunities we must not lose sight of the powerful influence that patient perception of our roles has over our practice. We should view patients as our monitors and listen to them.

Keys to success

- A shared vision, of service development and philosophy of care, within the multidisciplinary team.
- Collaboration with stakeholders, the multidisciplinary team and with service users.
- Managerial support including support for the development of nurses' skills and knowledge.
- Clinical supervision.
- User-friendly guidelines/protocols and care pathways.
- Effective documentation and record-keeping systems.
- The resources to facilitate the above.

In the past, Briggs agrees, many new roles have evolved in an *ad hoc* fashion, over a period of time, with little formal education or training, poor assessment processes, and poor evaluation of outcomes [6]. Again this highlights the need for good planning, a shared vision of service provision that is fundamentally about improved patient care

and supportive management. Supporting the development of nurses' roles requires the sustained investment of both time and money, and a willingness of doctors and professionals allied to medicine, to relinquish or share some aspects of their traditional roles.

Conclusion

Chris Beasley, Chief Nursing Officer for England [13], writes that in spite of all this change 'what patients want from nurses has changed very little… They [the patients] want contact with nurses that makes them feel safe, cared for, respected and involved.' This is the value base on which their trust rests, and on which the nursing profession is grounded. HIV patients are no different in this respect.

HIV services, like today's NHS as a whole, 'needs nurses who are intellectually able and emotionally aware' [13]. It needs nurses with an ability to combine technical clinical skills with highly effective communication and empathy.

There is a clear need for more research, particularly action research that looks to explore whether nurse-led care makes a positive difference. We need to evaluate the impact of such initiatives on patient satisfaction, clinical outcomes and treatment adherence, for example; as well as on cost, the impact on recruitment and retention and on our relationships with other healthcare professionals.

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Collaborative practice

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The last 10–15 years have seen a dramatic change to the face of HIV: the advent of life-saving antiretroviral therapy; the subsequent development of drug resistance; the emergence of toxicities and, for some patients, unrecognisable and debilitating body changes; and of course the significant shift in demographics. As a result of these changes, a power imbalance has been created within clinical practice. We have moved from a climate of shared knowledge between the patient and healthcare professional in the 1990s to one in which clinicians are at a significant advantage to the patient and other healthcare professionals in terms of knowledge and power particularly in relation to treatment developments. We now see many long-term survivors both on and off antiretroviral therapies – some of whom have been taking medication for more than 10 years – and many of whom naturally experience both treatment and disease fatigue, having had to deal with the reality of potentially reaching old-age when an extra 6 months seemed precious at the time of starting therapy. There is also a growing diversity of patients, particularly from among minority groups such as refugees and asylum seekers, for whom HIV is the least of their priorities. For these patients the medical model of treatment is simply not enough and a multi-disciplinary patient-centred approach is key.

It was with this in mind that the Kobler unit at Chelsea and Westminster hospital acknowledged that it was necessary to reorganise the delivery of care in order to maintain the high level of nursing care that had become the hallmark of the unit. After advice from the Richard Wells Centre for Research, it was recognised that success was more likely if nurses worked collaboratively with doctors rather than implementing purely nurse-led services (Cole S and Bruton J, personal communication).

Over the past two decades, the concept of collaboration has been seen as one that has a positive effect on patient care. There is a growing body of evidence that a collaborative approach is the most effective and efficient way of providing patient care; however, despite this evidence and widespread support, it is very difficult to achieve [1,2]. This is primarily due to the historical friction between doctors and nurses; a multi-faceted conflict rooted in a number of professional and social issues such as role definition and power, and based on traditional and historical boundaries that continue to exist and with which nursing continues to struggle. It is interesting to note that in much American literature in particular, when 'collaboration' is discussed in advanced nursing practice, it is often used as a euphemism for 'supervision' [3]. Arguably nurses have understood more than any other group of healthcare professionals that good patient care depends on the contributions and interactions of various providers. Collaboration requires sharing of information and expertise among disciplines that have traditionally worked independently. It also requires a sharing of power based on knowledge and expertise rather than title and role. This highlights a specific challenge for nursing, which has struggled for many years to identify its unique contribution to patient care.

A number of professional and legislative documents in the last 10 years have provided the impetus for the expansion of nurse-led services within a collaborative framework. The UKCC document *The Scope of Professional Practice* [4] allowed nurses to expand their roles on the back of the reduction in junior doctors' hours. More recently, *The NHS Plan* [5] focused on smarter working to maximise the use of talents within the NHS workforce. The Chief Nursing Officer [6] identified her 10 key roles for nurses, which form the core of development of nurses' contribution to the new NHS and include running clinics, managing caseloads, and ordering and interpreting investigations. The key message of all these documents is that the principles of collaboration are key to the health service delivering effective patient care, and that nurses can play a key part in breaking down barriers between professionals and in providing a patient-focused service.

The Kobler clinic remains the largest HIV unit in Europe with a patient population of approximately 5000. Prior to the implementation of collaborative practice, there was a very traditional set-up within the Kobler clinic. The unit was medically led and most clinics were doctor led. The outpatient nurses co-ordinated the day-to-day running of the clinic, triaged patients in the emergency walk-in service and generally troubleshot. Phlebotomy was the only real opportunity to assess patients and this was very informal and inconsistent as most patients expected this to be the least time-consuming part of their journey and did not appreciate having to wait their turn while the nurse discussed adherence with the patient before them. The other valuable opportunity was for seeing new patients, which was the only time the doctors formally referred patients. Most nurses had a small caseload of complex patients who they 'picked up'. The more senior nurses provided adherence support and counselled patients starting or switching antiretroviral

therapies although this was usually done by an HIV Clinical Nurse Specialist. Otherwise the nurses felt, and were viewed as, subordinate. There was a real awareness among the nursing staff that things could be done better; experienced staff members were frustrated at being unable to demonstrate their expertise and at the lack of role definition. Having bandied around the concept of collaborative practice for some time, a pilot clinic was set up. The clinic ran for one session per week and was led by a consultant. The team consisted of two consultants, one associate specialist, one specialist registrar, one senior clinic nurse and a research nurse. Our vision was to:

- Ensure standardisation of practice;
- Offer specialist advice every day;
- Maximise the opportunity for patients to access trials;
- Enable follow-up by the most appropriate practitioner;
- Maintain continuity of care;
- Maximise the use of clinic space.

The team met for a 20-minute pre-clinic meeting to discuss all patients booked into the clinic and appropriate referrals were made. For example, patients eligible for clinical trials were referred to the research nurse; medically complicated patients were referred from the specialist registrar to the consultant; and patients with adherence difficulties were referred to the nurse. The criteria for referral to the nurse clinic were as follows:

- Patients who are stable on antiretroviral therapies;
- Patients who are stable off antiretroviral therapies;
- Patients who require treatment support;
- Patients who have ongoing psychosocial needs;
- Must see consultant at least annually.

Any nurse running the nurse clinic had undertaken the adherence development programme run by the HIV Clinical Nurse Specialist and was very well supported by the clinicians within the team.

Patients seen in the nurse clinic requiring medical intervention were referred to any free doctors within the team and all patients were informed that they could see a doctor if they so wished, but most were happy not to. The pilot clinic continued for a further 18 months and was taken on by another consultant-led team, although rather differently. None the less, a local audit after 3 months revealed that patients were very happy to be seen by a nurse: they were satisfied with the care received particularly in terms of the amount of time spent with the nurse and the nurses' listening skills. No strong preference was expressed to see the doctor rather than the nurse and vice versa.

The next step was to roll out the concept across the whole clinic, which took a considerable length of time as it entailed getting all clinicians on board. Many were concerned about 'letting patients go' and, naturally, most did not want to be left with a caseload of only complex patients. However, by April 2005, team working was in place across the entire clinic. Three teams had been established, all led by a consultant. This set-up had been debated initially but eventually it was decided that it was most appropriate. The teams had a very similar set-up to that of the original pilot clinic team with the addition of more clinicians, a dietitian, a health advisor and a junior clinic nurse (associate nurse, Band 5) whose role was to see all new patients and do basic adherence assessments. All members of the team have allotted clinic slots with the exception of the research nurse and health advisor who see patients as required. As with the pilot clinic, there is a 20-minute pre-clinic meeting where all patients are discussed and if necessary allocated to the most appropriate practitioner. Sometimes new patients are referred from the consultant to the specialist registrar as they usually have longer clinic slots, and they then discuss the patient with the consultant as necessary. The primary nurse (Band 6–7) has six or seven 30-minute slots. Stable patients are sometimes referred to the nurse clinic on the day but it is more often suggested that these patients book into the nurse follow-up clinic next time. The meeting is also used as a good opportunity for education.

The concept of collaborative practice has generally been very well accepted and successful within the clinic. In at least two of the teams the primary nurse has built up a caseload of approximately 50 patients. On the whole, clinicians are supportive of the nurses' role and contribution. Anecdotally, patients have been very positive about the changes and have been happy to be seen by the most appropriate member of the team. We are in the process of undertaking an extensive patient satisfaction survey that will form a critical part of the evaluation of the changes that have been implemented. Smaller clinics have observed our set-up and have effected similar changes within their own settings.

Naturally there has been an element of resistance from some clinicians. This may well stem from an unwillingness to accept an ethos of equality over that of hierarchy. However, having said this, one of the most significant reasons for acceptance of the concept was trust. The same nurses were involved from the outset and the medical team witnessed first hand the commitment of the nurses to improving patient care through role development and collaboration. Over time the team became aware of the benefits of sharing the burden of challenging and complex patients, utilising and realising the skills of the different team members, and saw that this could really work.

In terms of fulfilling our vision, we have come a long way but we still have a way to go!

Standardising practice has been achieved to a great extent but this still requires a lot of work across the three teams. It has been identified that good leadership is crucial to effective collaboration and as part of our ongoing review of ways of working, it will be reconsidered who is best placed to lead a team. With the facility to access specialist advice, patients very rarely have to re-attend for dietitian advice, treatment support if seeing a doctor, or health advisor input. Clinical trials have definitely become more accessible because of the presence of a research nurse at each pre-clinic meeting. Follow-up by the most appropriate practitioner has been achieved very successfully. As a result of team working, some healthcare professionals seem much more aware of their limitations and can refer patients safely onwards without compromising care. Continuity of care has been well maintained for the majority of patients although it can differ from team to team. In terms of adherence support, team working has considerably improved continuity of care. Clinic space remains an ongoing issue due to our ever-increasing number of patients.

There is no doubt that the face of nursing has changed over the past two decades. Having decided not to implement purely nurse-led clinics within our unit, the roles of the nurses have developed as their expertise has been recognised. It has also been acknowledged that quality healthcare is delivered by interdisciplinary teams, not just doctors. It is only when we utilise a workforce that is not constrained to traditional roles and responsibilities that we can provide effective and efficient quality care.

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Nurse-led clinics

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There are plenty of reasons for developing nurse-led services and many of these are outlined and discussed in *Advanced and Specialist Nursing Practice* [1]. During the 1970s there were concerns that many nurses left the profession because there were few opportunities for career development and therefore a lack of job fulfilment. Nurse specialism was seen as a way of keeping a job interesting and challenging. It was also viewed as a way for nurses to gain recognition for their role in patient care and for them to be rewarded with fairer pay. Castledine and McGee [1] also explain that in the 1980s there were concerns that there would not be enough trained doctors in the United Kingdom and nurses were encouraged to specialise as a way of rationalising healthcare delivery. The development of nurses' roles was viewed as cost-effective and it was hoped that by nurses taking on medical duties it would give doctors the opportunity to move on and do other things. At the same time there was disquiet about whether the standard of patient care would be maintained but the many benefits to be gained from nurses extending their role were also recognised. It was found that nurses often went beyond just considering the patients' medical needs but assessed their social and emotional needs too and nurses were considered more flexible and better able to work in a multidisciplinary way. There have been many examples of nurses taking on traditional medical duties and now these skills are often considered part of basic nursing care and no longer just to be undertaken by specialist nurses.

Nurses taking on duties traditionally carried out by doctors can pose a number of problems too. While the challenge of taking on new duties is exciting, there can be drawbacks. Can the new duties be managed alongside existing responsibilities and if not to whom do you delegate them? Existing team members may already be overburdened and may resent being handed new responsibilities. When recruiting new members for the team, it may be more appropriate and in the patients' best interests to recruit a person with similar expertise. However, there may be pressure to recruit more junior and less-experienced members of staff in order to reduce costs. Both doctors and nurses can have reservations about letting someone else take on their duties and an overall concern may be that the team skills are being diluted. In this case, the desire to protect the rights of patients and to ensure that they continue to receive full support can result in resistance to developing a nurse-led clinic.

Some of these difficulties can be dealt with more easily by ensuring that all members of the team are fully involved in making service planning decisions. It is important to have regular meetings and keep appraisals up to date so that everyone is assured of their role and can understand and feel part of the shared aims of the service. New duties may then be seen as a way of developing a role rather than another burden. It is vital that nurses have the chance to discuss their ideas about the way they want to develop their role and what duties and tasks they want to take on. Often the way a nurse-led service develops is dependent on the relationship between the nurse and the medical team. While it is not always easy for doctors to accept nurses' needs to develop, and some nurses remain nervous about taking on new responsibilities, good progress is being made including the development of Nurse Consultant posts and nurse prescribing.

For all the good and not so good reasons that nurse-led services are being developed we must continue to do our best to balance protecting patients, protecting ourselves and delivering the best care we can. The work of the National HIV Nurses Association (NHIVNA) gives us the opportunity to learn from each other and this is why NHIVNA has been running workshops, providing study days and conferences, developing competencies and undertaking benchmarking projects. NHIVNA meetings also provide an excellent setting for exchanging ideas and networking.

Developing a nurse-led clinic

My experience of developing a nurse-led clinic, outlined here, is far from perfect but I hope to demonstrate how clinics can be developed despite all the difficulties.

In 1998 I took up my Specialist Nurse post in a sexual health clinic in a district general hospital in Manchester. Although it was the biggest sexual health clinic in the region, HIV care had historically been provided by the larger Infectious Diseases department on the outskirts of the city. One of their consultants ran a satellite clinic for about 100 patients in the Outpatients department once a week and the sexual health clinic itself looked after another handful. As the infectious diseases unit had a good reputation and was highly regarded it was not really possible at that time for the Sexual Health department to develop its own service. As well as other duties my key role was to support the HIV-positive patients in both services.

I set up nurse-led clinics straight away. They took place twice a week and were for taking pre-appointment blood tests 2 weeks prior to the medical review. At that time patients had blood tests only after seeing the consultant and the results were not reviewed until the patients' next appointments, usually 3 months later. In my clinics, as well as doing repeat viral load and CD4 blood tests, I was able to:

- Monitor blood pressure and check weights;
- Undertake baseline serology and to repeat them when necessary;
- Initiate vaccination programmes;
- Arrange annual smear tests for women;
- Ensure sexually transmitted infection screening was arranged.

The actions themselves may be viewed as traditional nurses' duties but my extended role meant that I initiated what tests were taken and when. Audit presentations often showed that these checks were missed during consultant appointments and by monitoring patients in a nurse-led clinic before their medical review, problems could be dealt with promptly.

The pre-appointment clinics meant I was able to ensure I regularly met all my patients and could assess their nursing needs. The clinics worked well and knowing the patients made it much easier to help them when they were unwell and when they needed support around starting or changing therapy. I could review what the doctor had discussed with patients at their last appointment which often helped them prepare for what might be discussed at their next. This was important when a patient was to start HIV therapy as I could discuss the therapy and options before they saw the doctor so that they felt better prepared at their appointment. For those on treatment I was also able to assess levels of adherence to drug therapy and offered adherence support to every patient.

As the cohort grew appointment slots were reduced and there was less time for nursing assessment and getting to know the patient. Eventually it became necessary to recruit support from the sexual health clinic staff although they had never previously worked with HIV-positive patients and had to be trained to take over this role. Due to demand the pre-appointment blood clinics now run every morning and afternoon and we recently recruited a clinical support worker to take over the pre-appointment blood clinics altogether.

A Band 6 and a Band 5 nurse have been recruited to support me with the other duties required in managing the HIV patient cohort, which is now around 900, and we have constantly had to review our roles and what we do. These changes have presented some difficulties for us all; it is hard to let go and can be confusing for patients too. Patients had been used to seeing an experienced nurse and often came to pre-appointment clinics with questions and concerns. When patients see me they can ask questions about their HIV and I can initiate actions such as further tests (e.g. resistance tests) if patients report a few missed doses or extra blood tests if they report new signs and symptoms. Our clinical support worker cannot be expected to do this so they are done when they see the doctor, which often results in them needing another doctor appointment later. The clinical support worker has to seek us out if patients raise concerns or have new problems, a situation that is inconvenient and causes delay.

Changes to the clinic

In other ways my role has changed considerably. The consultants' clinics were often overbooked and it became necessary for me to see patients. Initially I would see patients who were well and just needed results. Then I started to see patients who required prescriptions. Often, to facilitate this, I arranged for them to be written in preparation for clinic. At the time of writing the prescription the doctor had an opportunity to review the patient's file. This was most important as from time to time new data would become available that would require changes to drug combinations. We also agreed that the consultant would continue to dictate their clinical summary and this was again an opportunity for the doctor to ensure I had not missed anything.

As my experience increased, I began to see patients with more complex needs including patients with reduced cell counts. I might initiate discussions about starting therapy, redo blood tests including resistance tests and give written information in preparation for another appointment with the doctor when HIV therapy would be prescribed. This system ensures that all patients required to commence HIV therapy get a chance to talk about drug options and issues around lifestyle, adherence and resistance in preparation for their next visit. Unwell patients would be seen too and I would take a detailed history and a set of observations before the doctor reviewed them. Sometimes I might initiate an extra test like a pregnancy test or urinalysis or send them for chest X-ray before the doctor sees them.

Initially it might seem strange to patients that they are seeing a nurse instead of a doctor but many say that they prefer it. Some say this is because things are better explained, some because it ensures continuity if they already know me and some because they feel they can discuss things with me they might not raise with the doctor. On the other hand, there are those patients who only want to see the doctor, but the fact that there are nurses as well as doctors who can see patients means we can offer more choice and flexibility.

The consultants' clinics take place almost every morning and every afternoon and one evening a

week. Either the Band 6 nurse or I will try to be available to support these sessions as patients will be put through to see us should they need to discuss initiating or changing therapy or have any other nursing need. Sometimes there are double clinics, when two consultants hold clinics simultaneously, and we are kept very busy in our traditional nursing capacity. Ironically, at times when we are busy, the doctors may end up covering for us and will go through the issues around starting medication themselves. This flexible arrangement and crossover of roles works well and helps to ensure the patients get what they need while they are there and do not have to keep coming back.

As well as supporting the consultant sessions, we also run specialist nurse sessions almost all day every day. There are a growing number of patients who find it difficult to attend clinic at the clinic times. There are patients who live a long way away or who do not want to take time off work to attend. Nurses can sometimes offer appointments at alternative times, including evenings and even more patients are requesting to have their results by telephone. Test results can also be emailed or texted if the patient prefers. Prescriptions can be prepared in advance and left at the pharmacy to be collected directly at times more suitable for the patient, including Saturday mornings. These changes benefit the consultant clinics because there are more appointments available for needier patients; the patient benefits by avoiding long waits at the pharmacy when queues build up during clinic times; and the pharmacy prefers the system too. In the future we also hope to incorporate a home drug delivery service into our nurse-led clinic developments.

In these sessions we also see all newly diagnosed patients who are referred to us and the aim is for them to be seen within 1 or 2 days of receiving their positive result. As well as offering support and information and making an assessment of their financial, social and emotional needs, we also initiate baseline blood tests and patients return to us for these results a week later. Depending on the counts and what issues or needs the patient has we continue to see them weekly and will often see them two or three times before they have their initial doctor consultation. By doing this we can ensure patients have had information, explanation and support so that when they see their consultant they have had a chance to work through some of the initial concerns and worries their diagnosis has raised and they know what their baseline results are and understand the medical terms we use. Initial worries, for example, about contact tracing, testing children, the effect the diagnosis may have on work, information about safe sex, condom use and post-exposure prophylaxis and concerns about vertical transmission will have already been addressed. Patients who are unwell or whose baseline CD4 cell counts come back low will be fast-tracked to see a consultant but this way of working ensures all newly diagnosed patients have results of baseline counts within 1 week and that *Pneumocystis* pneumonia prophylaxis can commence at this time for those who need it.

Patients who are unwell or who are having problems or concerns about their medication are encouraged to telephone the specialist nurses first or may attend as walk-ins. These patients and those requiring post-exposure prophylaxis will be added into our specialist nurse clinic for advice and support in the first instance. Often, we can refer them on to their GP or elsewhere or if necessary one of the HIV consultant clinics. As well as those who walk in we get many telephone enquiries each day. For further advice and to discuss complex patients we meet twice weekly with the consultants who use these meetings to refer back to us patients who they feel need further support or follow-up from the specialist nurse.

As I have had to let go of more and more of my duties over time I now mostly meet patients when they are newly diagnosed and then when they are due to start HIV therapy and are referred back to me for support, which can be some years later. Patients miss out on the continuity I used to be able to provide when I saw them every 3 months to take their bloods and for me those were important opportunities to reinforce the benefits of a healthy lifestyle, to advise and promote good adherence to medication and to support people with issues that arise from time to time when living with HIV. I am concerned that patient care is suffering and it does raise important questions for me like how far can any nurse's role be developed? Is it appropriate that a clinical support worker is now providing a service previously provided by a clinical nurse specialist while I have taken on traditional medical duties? How do we as nurses explain to managers what we do so that it is valued and that new staff can be appointed at a similar level?

Guidelines and protocols

As we are a relatively new team of nurses and consultants in a relatively new HIV service, between us we can develop the service in our own ways. Specialist nurses are expected to be experts in their field, to be able to work independently and manage their own area of work. They should be abreast of developments in their area of nursing and be able to demonstrate evidence-based practice. Facilitating change and incorporating new ways of working is key to their role and they are best placed to initiate developments and often undertake new duties and skills themselves before then supporting others in doing so. A specialist nurse can do all the networking and planning to prepare for the service development and then test run it. I feel I have been given a fantastic opportunity to do just this in Manchester. Now that

we have established and agreed ways of working with the doctors we now have to put in place the guidelines and protocols to support practice.

Competencies are important and we are developing these too. It is essential that all members of the team are clear about what is expected and that they have measurable outcomes of training. Ideally, audits will support the service we provide and point out areas that need improving and modifying. We will endeavour to ensure that audit results are incorporated into any planned changes. Patient questionnaires may be used to check that patients are happy with our service and have their say about areas for improvement but they can also support service development particularly if an application for further funding is required.

Our unit is fast growing and chronically under-resourced for the number of patients in our care. It is therefore difficult to plan and make official any new developments and we still lack guidelines or protocols. We aim to meet regularly to formalise guidelines but as clinics over-run, meetings are cancelled. Without formal guidelines, it can be unclear where our boundaries, as nurses, lie and we end up doing a lot of things on trust, which is scary. To save time, we are currently looking into adapting guidelines prepared by other units (to whom we are very grateful for sharing their work), but our unit is still very much a work in progress.

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The role of the Clinical Research Nurse

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The role of the Clinical Research Nurse (CRN) within HIV nursing is a varied job, working in an extended and specialised role within multidisciplinary team settings. There can be enormous variability in the role and responsibilities of CRNs, however this article is aimed at providing insight to some of the aspects of the role, the knowledge and skills required, and the role progression.

A clinical trial is a research study designed to answer specific questions about vaccines, new therapies or new ways of using known treatments. Clinical trials (also called medical research and research studies) are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people. Trials are carried out in four phases: Phase I tests a new drug or treatment in a small group; Phase II expands the study to a larger group of people; Phase III expands the study to an even larger group of people; and Phase IV takes place after the drug or treatment has been licensed and marketed. We are all aware of the developments that have been achieved in the care and management of patients with HIV; these have relied on patients participating in clinical trials and in most cases there will have been CRNs involved in the recruitment, monitoring and follow-up of the patients in the trials.

It is essential that CRNs within HIV nursing have extensive and current experience in the care and management of people with HIV. As nurses, CRNs are also uniquely qualified to blend their communication, clinical and administrative skills, which are all necessary to conduct clinical research. The role of the CRN has proved difficult to define clearly as it has many facets. Prior to Agenda for Change, the publication of an employment brief for CRNs by the Royal College of Nursing (RCN) had redressed some of the imbalance, recognising in detail their role, knowledge, skills and expertise with appropriate grading and remuneration. However, this was a general brief and not specifically for CRNs working in HIV where the role has a greater extent. Agenda for Change brought variations across the country as there was no national profile for the role and it led to nurses being banded differently from one centre to another. Most CRNs are Band 6, with some doing the same role but at Band 7. The National HIV Nurses Association (NHIVNA) has developed competencies for HIV nursing. One of the specialist competencies is for the role of CRN – at the time of writing this article the competencies are out for consultation and are available on www.nhivna.org. It is hoped that the competencies will provide a framework that has previously been missing for CRNs.

All clinical research is conducted to recognised standards and regulations as laid down by governing bodies in the UK and internationally. This is to ensure scientific, ethical and clinical safe practice. Thus it is vital that the CRN has a full working knowledge of ICH Good Clinical Practice (GCP), the EU Directive for Clinical Trials and its implementation into UK law. A thorough understanding of these research regulatory requirements runs through all the responsibilities of a CRN across all the bands, through all the job descriptions and throughout the knowledge and skills framework. It is these requirements that are a defining difference between the CRN and other HIV nurses and their implementation is often a steep learning curve for nurses new in the role. On the positive side the regulations mean that with guidelines and standard operating procedures (SOPs) nurses have clear definitions about their roles and responsibilities and so what is expected of them is unambiguous.

It is acknowledged that the quality of clinical trials is improved when nurses are involved at the investigators' site [1,2]. The sponsors of clinical trials, usually the pharmaceutical companies, are more likely to work with investigators (HIV physicians) if they know there is a nurse or a team of nurses who will undertake the majority of the work. Some CRNs may work within dedicated HIV research units, usually within the larger HIV centres as part of a clinical trial research team; others may take on this extended role in addition to their usual responsibilities.

Roles and responsibilities

The CRN should work in conjunction with the site investigator, usually one of the HIV consultants, who will delegate many of the responsibilities to the CRNs, pharmacists and co-investigators who will be specialist registrars or research fellows. The knowledge, skills and expertise required by nurses for conducting the clinical trials include reliability, organisation, communication, motivation, self-discipline and critical thought. Good communication skills are vital to build relationships and communicate effectively with patients, members of the research team and sponsoring companies.

The responsibilities of nurses in the conduct of clinical trials are wide ranging and include the following.

Recruitment and screening of patients and ensuring informed consent has been given

The CRN acts as the primary advocate for the patient, both prior to and throughout their participation in a research study. While it is a doctor who has to take the informed consent it is the CRN who will assess the patient's suitability to participate in the study. It is important that time is spent with the patient discussing the study in detail, the aims and objectives of the study, the potential side-effects and risks as well as potential benefits. The patient needs to know what is expected of them, as participation in a clinical trial will often require additional follow-up visits to the clinic and may also require restrictions on diet or other medications. Women need to know that in the majority of studies pregnancy should be avoided and that barrier methods of contraception must always be used. The CRN will also enter into a discussion with the referring doctor if, in the nurse's opinion, a clinical trial is not in the patient's best interest. It is often the patient who says 'well my doctor thinks its best so I'd better do it' – this is not informed consent!

Follow-up and monitoring patients

A high level of detail when documenting in a patient's notes is crucial as all the information on the patient's progress needs to be documented. Any CRN will say that one of the challenges is ensuring that all documentation is accurate with start and stop dates of any adverse events or other medications taken. CRNs are often best placed to have that attention to detail. Good IT skills are also required as data is increasingly being captured and transferred electronically.

Career pathway

In their first role as a CRN, the nurse would be expected to understand the requirements of the study protocol, identify and screen potential participants, ensure informed consent is an ongoing process, organise and manage required procedures, assist with interventional treatments and record the resulting information.

As CRNs gain more experience they are expected to work with a degree of autonomy, frequently conducting concurrent research studies and so increasing their patient caseload. Organisational and project management skills are pivotal.

With further experience the CRN should have a sound knowledge of research design, methodology and understanding of the analytical and statistical processes. They would also have an active role in upholding the ethical requirements of a study and research ethics submissions.

Following on from that the CRN should have a research, educational and developmental role within the research projects. They should consider post-registration education in clinical research at a certificate level with progression to Master's level in clinical research. The Institute of Clinical Research (ICR) runs module courses leading to an MSc in clinical research.

The CRN would be expected to co-ordinate activities between the sponsoring companies and other departments involved in the research, as well as the immediate multi-disciplinary research teams within the department. CRNs at this level should have a clear overview, strategically and operationally, of the development of research projects. This lead role should include the development, assessment and supervision of research projects, the management and organisation of human and financial resources, including the negotiation of financial contracts with the sponsoring companies.

Summary

Ongoing training and experience ensure nurses develop management and organisational skills that enable them to be efficient and effective in the co-ordination of concurrent, complex research studies. Having theoretical and practical knowledge of HIV enables the CRN to understand the required objectives and endpoints of research studies while evaluating the validity of the tasks required for providing answers to the research question. The CRN will therefore also be able to disseminate the research findings to colleagues and other healthcare professionals enabling the development of evidence-based practice.

When discussing participation in a clinical trial with patients we are always impressed with the patients' willingness to do something for others. This altruism along with the desire of the patient to have access to new drugs or treatments and the feeling of safety that they have in being followed up closely by a nurse who is knowledgeable and accessible promotes a great working experience for both nurse and patient.

References

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NHIVNA update

The first announcement is now available for the 9th Annual Conference. It will be held in London 28–29th June 2007. The programme is very exciting with many excellent speakers and topics. The closing date for abstract submissions is 27th April – so there is still time for you to submit. There are also scholarships available to help student nurses, junior nurses and senior nurses attend. Further information on the conference, abstracts and the scholarship applications is available on the new-look website (www.nhivna.org).

The 6-week consultation period for the HIV competencies has now begun. Feedback is essential for them to be effective. Members will receive emails regarding this process. All relevant information is on the website (www.nhivna.org). Study days are planned around the UK to provide nurses with the theory around the competencies. The study days, which are free to members, will be held in London, Stirling, Birmingham and Manchester. The official launch of the competencies will be at the annual conference in June.

Thanks to all members who returned their questionnaires. We are collating the information from these and plan to feed it back to you. The information gathered will be of great benefit to us in ensuring members get what they need from our organisation.

Sheila Morris, Chair-elect, NHIVNA

National HIV Nurses Association

9th Annual Conference of the National HIV Nurses Association (NHIVNA)

28–29 June 2007 ▮ One Great George Street ▮ London

Sessions to include:

- Launch of the NHIVNA competencies;
- Working within networks and standards;
- Criminalisation, reckless transmission and sexual health;
- Managing adolescents and transitional care;
- Nursing projects in resource-poor countries;
- HIV and social exclusion.

Dear Colleague

It gives me great pleasure to announce our 9th Annual Conference, which will be held in London 28–29 June 2007. The conference will be held at One Great George Street, an award-winning central London conference centre that is situated close to many of the capital's major sights.

The programme is taking shape and we are delighted to confirm that many eminent speakers have agreed to participate.

One of the highlights of the conference will be the presentation of the very latest research, education and clinical practice initiatives in HIV nursing during the oral presentation sessions. I would like to encourage as many delegates as possible to submit abstracts for review. Please refer to the Conference Announcement that can be found on the NHIVNA website (www.nhivna.org/).

NHIVNA is also inviting applications for a number of scholarships and awards. Some are related to the submission of abstracts, but I would like to draw your attention especially to the awards directed at junior and student nurses that are designed to assist them to attend the conference.

As is customary, the Gala Dinner will take place on the Thursday evening of the conference and we anticipate an evening of good food, wine and after-dinner entertainment.

I look forward to welcoming you to London.

Nicky Perry
Chair, NHIVNA

Forthcoming Events

13th Annual Conference
of the British HIV Association (BHIVA)
with the
British Infection Society (BIS)
25–28 April 2007
Edinburgh International Conference Centre

1st Annual Conference
of the Children's HIV Association (CHIVA)
25 May 2007
Birmingham
International Conference Centre

9th Annual Conference
of the National HIV Nurses Association (NHIVNA)
28–29 June 2007
One Great George Street, London

11th Annual Resistance Meeting
26 September 2007
Church House Conference Centre, London

British HIV Association (BHIVA)
Autumn Conference
11–12 October 2007
Queen Elizabeth II Conference Centre, London

14th Annual Conference
of the British HIV Association (BHIVA)
23–25 April 2008
Waterfront Hall, Belfast

10th Annual Conference
of the National HIV Nurses Association (NHIVNA)
26–27 June 2008
Glasgow

For further information on these events, please contact:

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