Developing the role of the nurse specialist

The specialist nurse in HIV/AIDS medicine

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Summary
The management of patients with human immunodeficiency virus infection requires a multidisciplinary holistic approach. Hospital-based specialist nurses can both co-ordinate and facilitate their hospital care, and also ensure early and effective discharge back into the community.

Keywords: HIV/AIDS, nurse specialist, communication skills

The course of human immunodeficiency virus (HIV) is often unpredictable and complicated by multisystem pathology necessitating frequent admissions to hospital. People with acquired immunodeficiency syndrome (AIDS) have complex physical, psychological and social needs. Specialist nurses of sufficient seniority and experience can facilitate and co-ordinate care to ensure effective multidisciplinary practice. The nurse will usually be experienced in caring for people with HIV and will have undertaken an accredited course; some specialist nurses hold a counselling qualification. The nurse must keep abreast of new developments in this constantly changing field and attendance at research meetings is mandatory.
HIV infection represents perhaps the greatest new public health challenge this century and community nursing has an important contribution to make to holistic home care for people with HIV.¹ The hospital-based specialist nurse can oversee discharge of patients into the community, co-ordinate services and liaise with hospices. Regular multidisciplinary meetings should be held and the patient be invited to participate wherever practical. It is essential that professionals respect the autonomy of patients in determining the nature and course of their care and that care delivered is clinically, psychologically, culturally and spiritually appropriate.
It is beneficial for the specialist nurse to get acquainted with the patient when he/she is relatively well, to build relationships not only with the individual, but also their partner and family. HIV-related illnesses can be very debilitating and the nurse's role is to support the patient and carers during acute phases of the illness and following discharge into the community, thus ensuring continuity of care. Establishing effective communication with family doctors and community nursing services, and providing support out of hours ensures that the specialist nurse becomes a valuable resource.

Confidentiality

The stigma associated with HIV infection has resulted in confidentiality being a major concern for infected people. Family members may be unaware of the diagnosis or the patient's sexuality and professionals have a duty to respect patient's wishes regarding disclosure. It is essential that all members of the caring team are vigilant so as to avoid accidental disclosure of HIV status. Many patients have anxieties regarding their family doctor's attitudes and the possibility of confidentiality being breached, particularly in small communities. The best solution lies in an open and frank discussion of the ways in which confidentiality will be safeguarded and to be consistent in providing that service within the limitations of each practice.²

Education

Specialist support is essential in areas of low prevalence where staff may be unfamiliar with sophisticated techniques such as, for example, the management of Hickman lines. Shared care training is an effective method of teaching and establishing confidence. Inviting community staff into hospital to meet patients prior to discharge can aid trust and collaboration.
In the past, community nurses have not been expected to administer intravenous drugs. However, advances in treatment and early discharge from hospital have resulted in highly dependent patients returning home. Nurses have been encouraged by their professional organisations to assume responsibility for acquiring skills to fulfil obligations to patients. This drive to contain costs and maximise resources has led to nurses extending their practice to undertake some duties traditionally performed by junior doctors. The hospital-based specialist nurse has access to the expertise and advice of nursing and medical colleagues and is in a position to provide and co-ordinate education.

Education

- intravenous therapy: patients
- universal precautions: carers, staff
- awareness raising: prevalence, universal precautions, attitudes, sexuality
- nutrition

Box 1

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Infection control – universal precautions

- wear gloves when dealing with body fluids
- do not re-sheath needles, dispose of sharps into safe disposal containers
- decontaminate blood spillages with hypochlorite
- immediately wash off blood/body fluids on skin, eyes or mouth
- penetrating wounds: encourage bleeding, wash, and cover with dressing. Report to occupational health physician
- cover any cuts and abrasions on hands with a waterproof dressing

Box 2

Infection control policies

The role includes advising on infection control procedures and sound knowledge of the principles of universal precautions is necessary. Surveys of health care staff having been occupationally exposed to HIV show a sero-conversation rate of 0.4%. The most likely means of transmission of blood-borne viral infections such as HIV or hepatitis B to healthcare personnel is by direct percutaneous inoculation of infected blood by a sharps injury or by blood splashing onto broken skin or mucous membrane. Since it is impossible to identify all those who are sero-positive for HIV or hepatitis, it has been recommended that every patient be regarded as a potential biohazard. Therefore, healthcare workers should, as a matter of good practice, routinely use appropriate barrier methods which will prevent contamination by blood/body fluids.³

Patients with AIDS should not be routinely isolated. However, many patients prefer the privacy of a single room. Patients who have infections with the potential for nosocomial spread, eg, pulmonary tuberculosis, salmonellosis and have to be isolated will require extra reassurance and activity to relieve monotony.

Awareness training

Awareness training of all members of staff can help dispel myths regarding transmission of the virus. Training can also give staff the opportunity to discuss sexuality and their thoughts around HIV infection. Unfortunately, these sessions usually fail to attract individuals with judgemental attitudes or homophobic tendencies who are most in need of the information.

Nutrition

Nutrition is an important aspect of management. Patients are particularly susceptible to *Salmonella*, *Cryptosporidiosis* and *Toxoplasmosis* infection. We advise our patients to boil their drinking water, avoid undercooked meat, paté and soft cheeses. Eggs should be boiled for eight minutes and fruit and vegetables washed. Severe weight loss and wasting is a distressing manifestation of AIDS and nutritional supplements may be helpful. A dietician should be available to advise on special diets and every effort should be made to make meals tempting and attractive.

Counselling

Psychological and emotional support is essential at all stages of HIV infection. When counselling is not provided, severe psychological disturbances may result and suicides have occurred. Depression and stress are common and usually resolved with skilled and sensitive counselling. Possessing relevant information, skills and interest is often a more useful prerequisite than formal counselling qualifications.⁴

Interventions designed to alleviate anxiety include discussing with patients their fears, rationally highlighting their identifiable strengths to cope with stress, and encouraging socialisation and leisure-time activities.⁵ Antidepressant medication may be required and clinical psychologists can offer skilled assistance. Frequently patients lack social networks and feel isolated and self-help groups can be invaluable by offering mutual support. Patients may need to discuss the social implications of disclosing their diagnosis. It is imperative that nursing and medical staff are aware of exactly how much partners and families know about the patient’s condition before entering into conversation.

Most patients express fears, regarding pain, suffering and dying. Listening skills, reassurance and kindness provide comfort and support. Patients and families may also suffer from the stigma associated with HIV infection. Homosexual men frequently present with a complexity of interpersonal and psychological aspects of care.⁶ Many patients require assistance with financial and accommodation problems and support from social workers is appropriate.

No individual must be tested for markers of HIV infection without their true, informed consent. All specialist nurses should have acquired the skills needed to engage in counselling for HIV testing.

Multidisciplinary care of a patient with AIDS: case study

A 47-year-old highly independent man was living alone with late-stage HIV infection (box 5). Problems included poor mobility, cytomegaloviral retinitis and repeated chest infections requiring frequent admissions to hospital. The Nurse

Causes of stress in HIV infection

- progressive debilitation
- progressive changes in body image
- sensational media interest
- rejection by family, partner, friends, employer
- necessary changes in lifestyle
- fear of loss of confidentiality
- fear of death and dying
- self-blame and recrimination

Box 3

Challenging situations in AIDS/HIV

- the partner at risk who is being kept in the dark
- the wife who is unaware her husband is bisexual
- the relatives who ask searching questions regarding the patient’s diagnosis
- the HIV-positive healthcare worker
- the HIV-positive patient returning to a developing country

Box 4

Case study	
<p><i>Problems</i></p> <ul style="list-style-type: none">• breathlessness, impaired vision and poor mobility• precarious immunocompetent state (CD4 < 50)• cytomegaloviral retinitis requiring gancyclovir twice daily• cold, damp accommodation• social isolation• stress associated with progressive terminal illness	<p><i>Role of HIV/AIDS nurse specialist</i></p> <p>Assessment by community nurses, occupational and physiotherapists. Patient instructed in deep breathing and postural drainage. Bath and walking aids provided.</p> <p>Involvement of family doctor. Daily visits by community nurses.</p> <p>Education in management of Hickman line provided by specialist nurse.</p> <p>Assistance given with re-housing.</p> <p>Support from voluntary agencies. Respite care provided by local hospice.</p> <p>Patient and relatives received counselling and psychological support from specialist nurse and chaplain. Subsequently bereavement counselling offered to relatives</p>

Box 5

Specialist’s involvement included liaising with the multidisciplinary team, educating the patient and community nurses and providing psychological support. Respite care was provided by a local hospice. Despite his frail immunocompetent state the patient maintained his independence and undertook two visits to the US in his last year of life.

Palliative care

Palliative and terminal care of those dying with HIV-related disease presents particular challenges. Many patients are comparatively young and management may include the continuation of prophylaxis including intravenous therapy. High standards of nursing care are essential, with emphasis on pressure sore prevention and mouth care. Fresh linen, sponging and the provision of a fan can alleviate night sweats.

Symptom control can be difficult and staff need to be vigilant and monitor the efficacy of analgesia and anti-emetics. Specialist in palliative care can be consulted to give invaluable assistance. For patients who wish to die at home, all appropriate support should be arranged. Respite and hospice care should be available if the patient and carer feel they can no longer cope. Spiritual care must not be forgotten and the patient should have the opportunity to see their minister and participate in worship.

The expertise and experience of voluntary groups should not be underestimated. People who are reluctant to use local community services will often accept help from these organisations who have made an important contribution to effective home care for people with HIV. Many patients find alternative therapies such as aromatherapy and reflexology helpful in reducing stress and other symptoms. Finally, we must remember that the right to confidentiality continues after death and the diagnosis of AIDS should not appear on the death certificate.

Summary

Caring for this largely well informed, articulate group of patients is both challenging and rewarding. Diagnosing and treating the many clinical manifestations of HIV infection taxes the most experienced clinicians. Communications within the multidisciplinary team must be consistent and confidential if we are to maintain the trust of the patient. The specialist nurse is well placed to liaise, facilitate, and ensure continuity of patient-focused care from hospital to the community.

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3 Department of Health. *Guidance for clinical health workers. Protection against HIV and hepatitis viruses. Recommendations of the Expert Advisory Group on AIDS.* London: Department of Health, 1990.

4 Miller D. Counselling and psychosocial intervention. In: Adler MW, ed. *ABC of AIDS.* 2nd edn. London: British Medical Journal, 1991.

5 Pratt R. *AIDS. A strategy for nursing care,* 3rd edn. London: Edward Arnold, 1991.

6 Jones A. Nothing gay about bereavement. *Nursing Times* 1988; 84: 55, 57.