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ABSTRACT

Aims and Objectives

To systematically identify and critically examine the evidence on the contribution of the HIV nurse specialist to provision of HIV care in the UK and other developed countries.

Background

The HIV clinical nurse specialist role has evolved over the past two decades in response to changes in two areas of HIV care: Firstly changes in the treatment and care of those with HIV and secondly changes and development in advanced nursing practice. The challenges facing HIV care require the development of innovative services including a greater contribution of HIV specialist nurses. A review of current evidence is required to inform developments.

Design

A scoping review.

Methods

A broad search strategy was used to search electronic databases. Grey literature was accessed through a variety of approaches. Preference was given to UK literature with inclusion of international publications from other developed countries where relevant.

Results

14 articles were included. Four themes were identified: The diversity of the clinical role; a knowledge and skills framework for HIV nursing practice; the education and training role of the HIV nurse specialist; and the effectiveness of the HIV nurse specialist. The findings mainly focus on the clinical aspects of the role with little evidence concerning other aspects. There is limited evidence to indicate clinical effectiveness.

Conclusions

HIV care is facing substantial challenges and there is a clear need to develop effective and efficient services, including expanding the contribution of HIV nurse specialists. Such developments need to occur within a framework that optimises nursing contribution and measures their impact on HIV care. This review provides a baseline to inform such developments.

Clinical relevance

Current understanding of HIV nurse specialist provision to inform service development and optimisation of patient care.

Key words:

HIV; clinical nurse specialist; advanced nurse practitioner; scoping review.

INTRODUCTION

The HIV clinical nurse specialist (CNS) role was established in the early days of HIV care and has evolved over the past two decades in response to changes in two areas. Firstly changes in the treatment and care of those with HIV and secondly changes and development in advanced nursing practice.

Changes in the treatment and care of those with HIV

The most significant factor in the treatment of HIV is the development of highly active, antiretroviral therapy (HAART) that became available from the late 1990's and had a profound effect on the lives of people living with HIV (Mocroft *et al.* 1998, Palella *et al.* 1998). Before this time a diagnosis of HIV was often seen as a death sentence, and much of the AIDS health care was palliative (Egger *et al.* 1997, Cooper 2008). HAART has offered substantial improvements in quality of life and life

expectancy to the extent that HIV is now considered a long-term condition (McManus et al. 2012). Health care needs have changed dramatically as a result and placed different pressures and demands on health care provision.

The number of people living with HIV in the UK has increased year on year and is estimated to be 96,000 in 2011 (Health Protection Agency 2012). The numbers accessing care have trebled since 2000 and the costs to the NHS are estimated to be in the region of £1 billion a year (House of Lords 2011). The existing model of care in which the burden of HIV care is shouldered by hospitals was identified as unsustainable as early as 1990 (Smits 1990) and has become increasingly so. The HIV and AIDS UK Select Committee was commissioned in 2010 to examine progress made in tackling HIV and to propose recommendations to move the situation forward. Their report 'No vaccine no cure: HIV and AIDS in the United Kingdom' (House of Lords 2011) made a number of recommendations for improving existing services including the development of virtual and nurse-led clinics. They also emphasised the need for fundamental changes to the way in which HIV services are organised with greater involvement of community provision.

The Select Committee recommended that any new model of care delivery should be integrated within clinical network arrangements. This supports UK policy for HIV/AIDS care to be provided through clinical networks comprising partnerships across geographical boundaries and across agencies including local government and other partners (BHIVA 2012, BHIVA 2007). These networks offer a number of benefits: They allow care to be standardised, bring care closer to patients, facilitate the involvement of primary care, and maintain clinical standards by ensuring that health care professionals do not practice in isolation (House of Lords 2011). However, it is not clear how care should best be organised within those clinical networks. A systematic review of the literature identified significant gaps in evidence around what settings are most effective, how services should be organised to maximise beneficial outcomes, and what types of health care workers and teams are best able to provide effective HIV/AIDS care (Handford *et al.* 2009).

Development of the HIV nurse specialist role.

Nurse specialist roles developed in the UK in the 1980's and were expanded further with the establishment of the nurse consultant (NC) role in the NHS as part of the government's strategy for the nursing profession (Department of Health 1999). In common with many other countries, these roles developed as a response to challenges facing healthcare systems and the need to optimise the contributions of all members of the healthcare team (DiCenso & Bryant-Lukosius 2010). There is some comparability in the role and scope of these specialist practitioners between the UK and countries such as the USA and Australia (Schober & Affara 2006) although this is less so for the advanced roles of NC. Advanced nursing practice (ANP) roles are understood in terms of core functions although these are less clearly defined for the CNS than the NC. Whilst the CNS role has developed in terms of specific domains of practice (Glover et al. 2006) the NC role in the UK was established with four functions: expert practice, leadership and consultancy, education and training and service development, research and evaluation (Department of Health 1999). Another key feature of the UK context is the distinction between the two roles with the NC separate from and senior to the CNS (Kennedy et al. 2011).

There is significant interest in developing and expanding the specialist nursing contribution to HIV care. Their greater involvement, particularly in the care of stable HIV patients and developing community provision of care for this group of patients, has received widespread professional support (BHIVA 2012, BHIVA 2007, Royal College of Nursing 2011). It offers potential benefits in three broad areas: Benefits for patient care as a result of improved care alignment for medical and nursing staff; more effective use of medical and nursing resource; and increased cost effectiveness of HIV health care services (BHIVA 2012, BHIVA 2007, Trimble 2009).

The challenges facing HIV care mean there is an urgent need for development of innovative practices that offer "more for less" (Boyd & Cooper 2012, p.1860). This is likely to include increased and expanded involvement of HIV specialist nurses across all health care settings. A necessary first step is a review of the existing evidence base to inform these service developments.

AIMS

The aim of this scoping review is to systematically identify and critically examine the evidence on the contribution of the HIV specialist nurse to the provision of HIV care in the UK and other developed countries.

METHODS

A scoping review was carried out. Scoping reviews are characterised as a broad based and preliminary assessment of the available literature in order to identify the nature and the extent of the research evidence available (Grant & Booth 2009). Their analytic approach examines both the quality and the quantity of the existing evidence as the basis to understanding the current state of knowledge and identifying gaps in the evidence base.

Search strategy

Journal articles were obtained by searching electronic databases through OvidSP (2012, accessed from http://ovidsp.uk.ovid.com/) and through NHS Evidence (https://www.evidence.nhs.uk/). Databases included in the search were Ovid Medline, Allied and Complementary Medicine Database (AMED), Excerpta Medica database (EMBASE), British Nursing Index (BNI) and Cochrane. These were searched using free text search terms in the title and abstract, and subject headings (where available). These included HIV, nurse, specialist, consultant, nurse clinicians, nurse roles, referral, consultation, nursing models, nursing specialties, nurse practitioners, job description. The search was limited to papers published in English, and to literature published from 2000 to 2012 because of the profound changes in HIV care and to the lives of HIV patients since the introduction of HAART.

Articles identified through database searching were supplemented with others identified through web searching, reference lists, and seeking recommendations from experts in the field. Preference was given to UK literature, and international publications from other developed countries were considered where relevant. Literature from developing countries was not included because of the significantly different contexts in which healthcare is provided and accessed. Studies of all methodological types were included. Due to the limited evidence-base existing on the subject area, we did not consider it appropriate to use detailed inclusion criteria or a formal quality assessment tool.

Selecting and reviewing evidence

Search results were initially screened by title to reduce the number of results. Abstracts of the selected titles were then reviewed further to investigate if the article was relevant to the aim of the literature search. Two screening questions were used to determine relevance. Papers were included in the review if a) their primary focus was on specialist nurses in HIV care and b) they either provided detail insights into the role or reported assessment or evaluation of contribution to care. Initial screening was undertaken by ST, and the decisions were reviewed in discussion with HP and CB.

Search outcome

In total, 14 articles and additional records were identified as relevant to this review. The majority of included studies were descriptive, detailing aspects of HIV nursing care practice. The search outcome is shown in Figure 1. The included papers were read in full and descriptively summarised using a data extraction sheet in relation to their aim, methods, context, and results (Figure 2).

During the screening process four themes were identified; the diversity of the clinical role; a knowledge and skills framework for HIV nursing practice; the education and training role of the HIV nurse specialist; and the effectiveness of the HIV nurse specialist. These themes are used to structure the results of the review.

In this review we use the generic term "HIV nurse specialist" to include the full range of advanced nursing roles. Where individual studies have identified specific role titles, we use the titles described in that study.

RESULTS

The diversity of the clinical role

Several studies provide descriptive accounts of the role. Collectively they demonstrate how the role has evolved in a diverse number of ways, according to need. This diversity is seen across multiple contexts including urban and rural settings; low prevalence and high prevalence HIV infection areas; with different patient groups; and across the continuum of care from the hospital to the community.

Broughton (2011) describes a community based role in an area of low HIV prevalence. Her account demonstrates a wide ranging and diverse role that fulfils a wider social care function as well as a clinical function. Care is directed towards supporting patients to engage more fully with their HIV care and is provided through a variety of means including telephone calls and home visits. The role includes providing practical support with housing advice, debt management, psychological issues, understanding disability benefits, and help with return to the work place.

Totterdell (2009) similarly describes a varied role, working across the hospital, community and social care settings, for a practitioner working in an urban low prevalence area of the UK. She identifies key areas of the work to include home visits to help patients with adherence, or with complicated social issues. She also details the provision of nurse-led outpatient clinics for the management of asymptomatic patients. In this setting, care provision includes preparing patients to start treatment, and supporting those who are on treatment through regular medication review, symptom management, and facilitating patient engagement in their treatment. Totterdell also goes on to

describe how, as a member of the hospital multidisciplinary team, the HIV nurse specialist fulfils an outreach role, bridging transition of patient care from a hospital to community setting.

De-Sammy (2004) draws our attention to the importance of the HIV nurse specialist to account for the ethnic background and cultural values of the patient. This discussion paper looks at the CNS caring for HIV-positive black African women with a focus on sexual and reproductive health issues, which require the CNS to understand these from the patient's perspective. This is particularly important in light of changing demographics of the HIV population, and the implications of different care needs for different groups.

Two papers provide insight into how the role is realised in urban high prevalence areas and demonstrate its development. Mabey-Puttock (2007) provides a UK perspective and describes a role concentrated on clinical care. She details the establishment of a nurse-led clinic that was developed to operate in conjunction with medical reviews. The focus of care was upon monitoring and supporting adherence, but included a broader supportive and educational component. She provides valuable insight into the way that this nurse-led provision has evolved in response to demand. Initially established to provide care for patients whose condition was stable, the clinic and the role of the nurses has expanded to support an increasingly diverse group of patients at different stages of the disease trajectory with complex physical and psychosocial needs.

Spirig *et al.* (2004) report on a three-year project to develop a team of HIV specialist nurses within a hospital outpatient department in Switzerland. They used participatory action research to initiate change in three areas: The culture and organisation of the clinic; clinical leadership and interdisciplinary collaboration; and the development of new services. Through a systematic process of education, the nurses developed specialist skills, knowledge and expertise. Subspecialisation within the team in areas such as medication and symptom management enabled individuals to expand their role in specific aspects of care and enhanced the collective expertise within the team. In conjunction with this work, a critical examination of the existing service provision lead to a reconceptualisation of care with the identification and implementation of several new approaches. Evaluative data indicates that the project produced several benefits for the workforce including an improved working environment and improved interprofessional collaboration.

In summary, these papers indicate the diversity of the clinical role with substantial differences evident between high and low HIV prevalence areas and rural and urban settings. It demonstrates how the role has evolved in response to patient need and service provision. In high prevalence areas, the size and the complexity of the caseload supports a large multidisciplinary and highly specialised workforce and provides opportunity for the nurses to become highly specialised in specific aspects of care. In contrast, low prevalence areas are unlikely to support a multidisciplinary diverse specialist workforce and the nurses' role expands accordingly to provide services that would be provided by social workers and social psychologists in other contexts.

A knowledge and skills framework for HIV practice

The Royal College of Nursing (2011) states that it is essential for nurses working in HIV to have the knowledge, skills and competence to agreed standards to improve effective delivery of interventions. The UK National HIV Nursing Competencies were developed by the National HIV

Nurses Association (NHIVNA) and have been in place since 2007. This competency framework was developed to complement the generic knowledge skills framework that was introduced in the NHS in 2004 (Department of Health 2004). It defines the knowledge and skills required for HIV nursing care, and provides a structure that can be used at national, service and individual level.

The framework covers two domains of practice, namely generic and specific aspects of HIV care, and details three competency levels (levels two to four) to reflect differing levels of expertise. Levels three and four relate to specialist roles with level three reflecting the CNS role and level four the expert practitioners working in advanced practice roles such as nurse consultant and senior clinical practitioner. Some initial work has been undertaken to examine uptake and implementation of the framework.

NHIVNA conducted an online evaluation of the competency framework among its 251 members in 2010 (NHIVNA 2010). 29 people from across the UK and one from Australia completed the questionnaire giving a response rate of 12%. 97% of respondents were aware of the competency framework and 93% had used it in their practice. This is unlikely to reflect the national picture as those using the framework are more likely to have completed the questionnaire than those who are not. Respondents reported that the framework had been used for a number of purposes including education and training, professional development purposes including appraisal, and service development including setting up nurse-led clinics. The extent to which the benefits of the framework had been assessed was variable. The majority (83%) had not measured benefit to their service, however a greater proportion (87%) had measured benefits to patients, although the indications are that this was largely informal or using indirect indicators.

These preliminary findings suggest that the framework is valuable for developing and supporting HIV nurse specialist roles, however further more detailed work is indicated. One specific area identified by the respondents was the ways in which the framework could be used to measure clinical effectiveness and assess the impact of the HIV nurse specialist role.

The education and training role of the HIV nurse specialist

The HIV specialist role includes an educational and training component but this has received little attention in the literature. Totterdell (2009) and Nokes (2000) both describe a role that involves formal education for a variety of health care professionals, from student nurses to those specialising in HIV or blood borne diseases, and those working in community settings. Broughton (2011) also identifies the support provided to other community medical and nursing practitioners, with the aim of equipping them with the confidence and competence to care for this group of patients.

To date, no work appears to have been done to capture the impact of this role and the contribution that it makes to the wider provision of HIV care.

Effectiveness of the HIV nurse specialist

Seven studies examined three aspects of role effectiveness: patient satisfaction, clinical outcomes and cost effectiveness.

Two studies provide patient perceptions of care. A cross-sectional survey in the Netherlands (Hekkink *et al.* 2005) evaluated patient perceptions of care quality using the QUOTE-HIV questionnaire method of assessment (Hekkink *et al.* 2003). Care was evaluated according to professional performance, professional attitudes, and organisation of care with 226 patients, 153 of whom had had contact with an HIV nursing consultant (HNC). The overall quality of care provided by the HNC was judged to be "good" and was comparable with that provided by the GP and HIV specialist physician.

Griffiths *et al.* (2007) present a qualitative study conducted in London. They focused on one aspect of care and reported on patient experience of a nurse-led treatment advice clinic (TAC) and its effect on adherence. The TAC was available to patients who had been advised to start/change HAART, and those wishing to discuss problems with their current therapy. The service was beneficial to patients because it offered simple, interactive and practical treatment advice alongside close patient monitoring to improve adherence. In this study, data collection consisted of 17 consultation observations and 10 patient interviews. The results were positive. Patients reported that the provision of regular telephone support to check on progress was particularly beneficial because it provided reassurance, removed feelings of isolation, and encouraged adherence. The authors also suggest that the telephone support had the added value of saved time and resources, however no empirical evidence is given to substantiate this.

Three papers focus on clinical effectiveness and resource management. From the UK, Auweiler (2011) and Bennett and Jones (2008) report that within the context of HIV/AIDS patient care, nurse specialists with extensive knowledge in prescribing and monitoring for stable patients have the potential to improve the effectiveness of resource management. However the empirical evidence from these two references is limited. Auweiler provides expert opinion. Bennett and Jones report their findings from a qualitative study that examined the experiences of independent nurse prescribers (INP). The study, which consisted of a questionnaire and focus group, was considered to represent the majority of INPs in HIV care at the time. The respondents reported that INP had improved service efficiency and reduced waiting times with more effective use of nursing and medical time although data were not collected to substantiate these reports. Findings from the focus group provided insight into the challenges faced including prescribing pressure from patients and organisational barriers. These preliminary insights are important in understanding the realisation of role expansion although further work is clearly indicated to explore in more detail the impact they are having on service provision and resource management.

Wilson *et al.* (2005) provide substantially more robust evidence to support the suggestion that the HIV nurse specialist has the potential to improve the effectiveness of resource management. This was a multi-site cross sectional study in the United States to evaluate the quality of care provided by HIV nurse practitioners (NPs), physician assistants (PAs), and physicians. 243 clinicians were surveyed and medical records for 6,651 HIV or AIDS patients were reviewed against eight care quality measures. The authors reported that NPs and PAs had higher performance rates for purified protein derivative testing compared with physicians (p<0.05); and higher performance rates for Papanicolaou smears (p<0.05). For the remaining measures (HAART use, control of HIV viral load, influenza vaccine use, and visits) rates were higher for NPs and PAs than for generalist non-HIV experts (p<0.05) and were similar to infectious disease-trained physicians and generalist HIV experts.

Their conclusions are similar to Hekkink *et al.* (2005). Wilson *et al.* conclude that the quality of care provided by NPs and PAs was comparable to that of physician HIV experts, and generally better than physician non-HIV experts. In their analysis, Wilson *et al.* grouped the NPs and APs together and provide no individual results for either group. This clearly limits the confidence with which the findings can be applied to either of the two groups. However, as the NPs represented 77% of their sample (51/66), it is likely that their findings indicate the effectiveness of the NPs.

Only one study provided information concerning cost effectiveness. Vervoort et al. (2010) conducted a descriptive study to report the potential of HNCs caring for HIV patients in Dutch outpatient clinics to reduce health care costs. Data were obtained from 14 face-to-face and 10 telephone interviews with HNCs that focused on the treatment team, the organisation of outpatient clinics, standards of care, and frequency of patient consultations. The study found that the outpatient clinics were predominantly provided by HNCs on the basis of substitution (HNCs as a substitution for care formerly provided by a physician). The consultation with the HNC consisted of a check of the patient's condition, discussion of the results of their blood tests, and support with emotional, psychosocial, and sexual health and adherence. In the case of deviating lab results or physical problems, the HNC planned further care based on hospital guidelines or in discussion with a physician. Overall, the authors found that HNCs have a stronger focus on adherence than physicians, and have more frequent contact with patients, factors that both need to be incorporated into any economic comparison of health care providers. In their conclusion, they suggest that the substitution care model has the potential to reduce health care costs because it reduces the number of physician consultations, however the basis of their claim is weak because it does not take into account the full range of their findings.

In summary, there is an overall lack of information about role effectiveness. Notwithstanding this, there is promising evidence from a UK and a non-UK setting to suggest that the care they provide is highly acceptable to patients who value their contribution. There is also evidence from a non-UK context that they are clinically effective in specific aspects of the role, most clearly around medication management and treatment adherence with outcomes comparable to or better than medical practitioners. To date there has been no assessment of cost effectiveness.

DISCUSSION

This scoping review provides a timely examination of the evidence relating to HIV specialist nurses. There are a number of limitations: The time limits were set at twelve years to ensure that we captured as wide a range of the literature produced since the introduction of HAART. However, we acknowledge that in this rapidly changing field, the role will have evolved and therefore some of the descriptive accounts may not reflect current practice. Our search strategy enabled us to capture important grey literature but we are mindful that this work may not have been subjected to the peer review process. Finally our inclusion of international literature ensured a comprehensive evidence base, but the very different health structures within which the studies were conducted need to be taken into account when generalising their findings to the UK context.

Notwithstanding these limitations, this review provides an important baseline to inform development of HIV services and how the contribution of the HIV nurse specialist can be optimised and evaluated.

In 2013, changes will occur in the funding of HIV care in the UK. This reflects a global imperative to optimise HIV care and service delivery in a financially constrained environment (Boyd & Cooper 2012). A pathway system of payment by results will be introduced in the NHS which will reflect the different levels of complexity and cost associated with caring for patients who are medically stable in comparison with those who have complex co-morbidities, and those who are newly diagnosed or just starting therapy (Department of Health 2012). This structure provides opportunity for a broad demarcation of service provision with complex care continuing to be led by specialist HIV physicians, and the development of alternative models of care for patients in the medically stable group. The pathways recognise that patients can move between different categories of complexity over their life course. This funding arrangement will serve as a powerful catalyst to widespread implementation of changes in the organisation and delivery of care.

The role of the HIV nurse specialist needs to be fully incorporated into these service developments to ensure that their contribution to care is clearly articulated and fully maximised. The work undertaken by Spririg *et al.* (2004) provides valuable insights into how a systematic analysis of service provision and a commitment to service development can produce substantial change in the nursing contribution to care over a short time period. It is critically important to ensure that services are developed within a robust structure in order to provide sustainable high quality care in this rapidly changing area of practice.

The NHIVNA competency framework (NHIVNA, 2007) and the HIV/AIDS clinical network (BHIVA 2012) provide that structure. The NHIVNA competencies offer a framework for service needs analysis and can usefully inform where and how specialist nurses are incorporated into HIV teams. They also provide the means by which the need for differentiated roles within the nursing contribution can be identified. At an individual level they provide a benchmark against which to plan and assess ongoing clinical and academic development to maintain high standards of care. Although evaluative data on the use of the framework were limited, primarily as a result of the low response rate to the online questionnaire, the findings were encouraging, demonstrating that when it is being used it is valued (NHIVNA, 2010). However further work is needed to explore its use in a diverse range of settings and service configurations and understand how it can be used to best effect.

Spirig *et al.* (2004) identified processes that were introduced in their project to facilitate interprofessional collaborations within an HIV team and the benefits that accrued. The clinical network structure offers a more comprehensive framework within which these processes can be effectively implemented because it provides opportunity for interprofessional collaborations within and between services and sharing of knowledge and expertise. Despite the challenging economic climate, it is imperative that services provide a systematic approach to role development, and nurture an environment within which that development can occur. HIV nurse specialists are well placed to respond to the increasing demands that will be placed upon them if there is adequate investment and resourcing to ensure that they remain a knowledgeable and highly skilled workforce.

Assessing the cost effectiveness of a health intervention through synthesising effectiveness and outcomes information with the financial implications is an essential step if evaluation is to inform decisions about resource allocation. A comparative approach provides the foundation for this but it

must reflect true differences between interventions (Russell *et al.* 1996). The evidence to support claims of clinical effectiveness (Wilson *et al.* 2005) and cost effectiveness (Vervoort *et al.* 2010) is limited and relates to non-UK settings. Furthermore, the premise on which both studies are based, namely role substitution, is problematic because it fails to acknowledge the specific skills and expertise that either professional group contributes to HIV care. Assessment of the nursing contribution should include their ability to influence patient experience of care. This is a critical aspect of the role given the long-term nature of HIV care.

The focus on clinical outcomes also fails to acknowledge the wider contribution of the role. For example the impact of educational activities with non-HIV specialist staff and the patient experience, which will influence uptake and effectiveness. Work in other areas has assessed specialist nurse contributions through controlled trials (e.g van der Hout 2003, Albers-Heitner *et al.* 2012, Albers-Heitner *et al.* 2011) but this approach would pose substantial problems in relation to HIV care. The primary measures of cost effectiveness in HIV care are drug costs and onward transmission of infection and the outcomes through which these are achieved are diverse and often difficult to measure.

Increasingly commissioning requirements include key performance indicators (KPI). Evaluation of service delivery needs to reflect these in terms of measurable outcome indicators within the KPIs. The effectiveness of HIV nurse specialists should be assessed against KPIs by first identifying those outcomes on which they have the ability to have a significant impact, and then developing a robust means by which to measure those outcomes. This approach offers a more sensitive assessment of effectiveness. It also provides a means by which to measure the wider impact of the HIV nurse specialist for example the education and support provided to non-HIV specialists and the impact that it has on early detection of infection. A toolkit recently developed to measure impact of nurse consultants provides insights into how this might be achieved (Gerrish *et al.* 2011).

CONCLUSION

This review of the literature details current understanding of the role of HIV specialist nurses and the contribution that they make to HIV care. There is some evidence to indicate effectiveness although the nature of this evidence limits claims of effectiveness impact, particularly in the UK context.

HIV care is facing substantial challenges and there is a clear need to develop effective and efficient services that include expanding the contribution of HIV specialist nurses. Such developments need to occur within a framework that optimises the nursing contribution and measures the impact they have on HIV care. The findings from this review provide a baseline that can usefully inform such developments.

RELEVANCE TO CLINICAL PRACTICE

This paper reviews current understanding of HIV specialist nursing provision. It details the changing context of HIV care provision and the need to maximise the contribution of specialist nurses to optimise patient care.

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