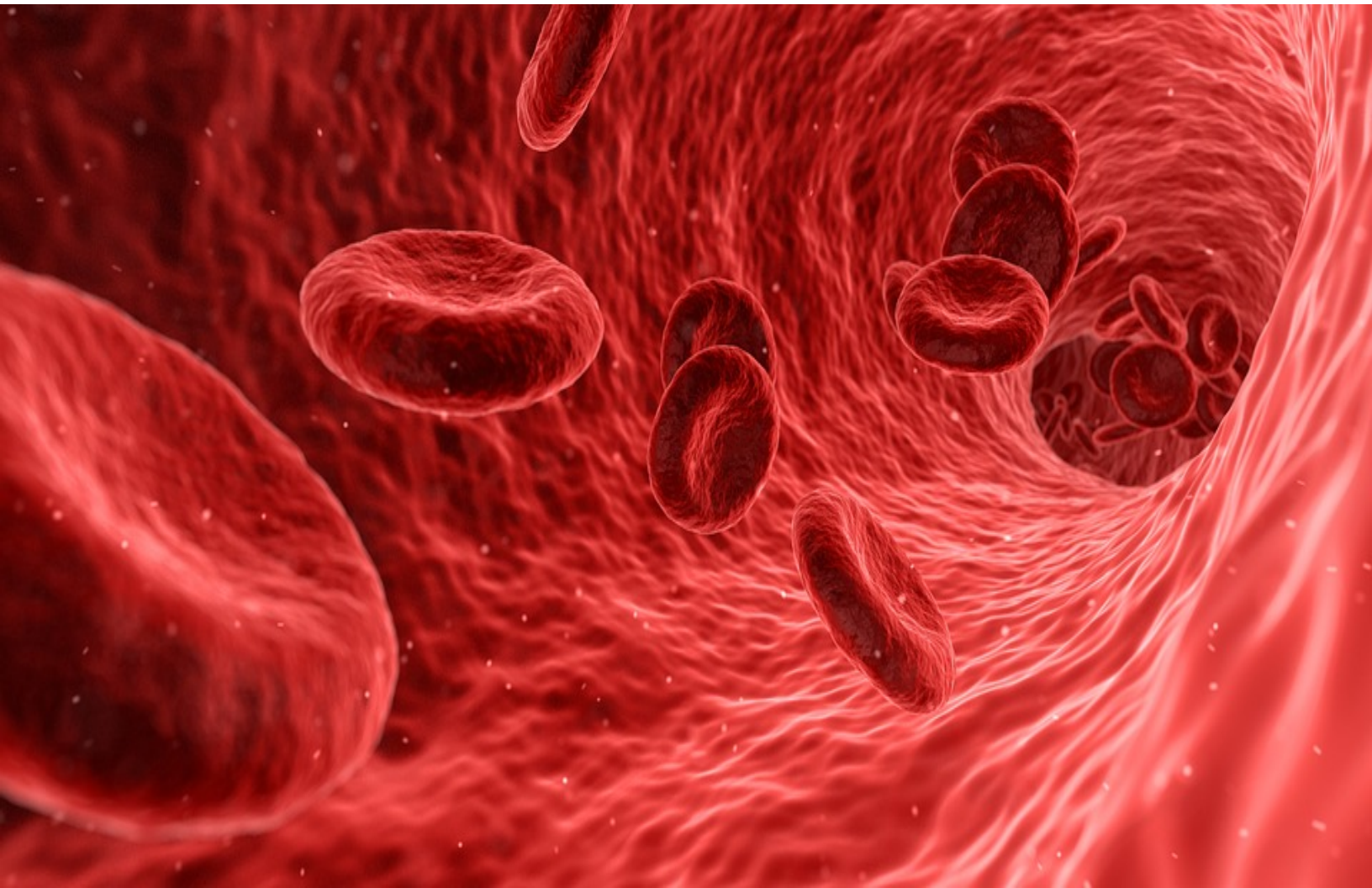


Haemophilia: The Role of Nurses



US haemophilia centre nurses and advanced practice providers: Demographics, roles/responsibilities, training, educational barriers and employment benefits

Introduction: As the focus on personalised treatment is refined, more products are brought to market and the life expectancy of persons with haemophilia increases, there will be an expanded need of experienced and expert healthcare providers to ensure optimal patient outcomes.

Aim: This survey describes the demographics, roles/responsibilities, practice patterns, educational opportunities/barriers and employment benefits of nurses and advanced practice providers (APPs), including advanced practice registered nurses (APRNs) and physician assistants (PAs) employed by haemophilia treatment centres (HTCs) across the United States.

Methods: This one-time convenience online survey was approved by the Munson Medical Center Institutional Review Board. A survey of this type had never been attempted in the HTC nursing community; therefore, there was no opportunity to utilise a

previous tool. Data was analysed using statistical tools through SurveyMonkey.

Results: Gaps were identified in provider age distribution, research opportunities, and standardised educational opportunities for APPs. An aging but highly educated HTC nursing population is revealed: over 50% of respondents were over the age of 50; the majority held at least a baccalaureate degree and almost half had national board certification; most were experienced in healthcare but newer to the field of bleeding disorders.

Conclusion: Development of an APP fellowship program would standardise the care and treatment of those with bleeding and clotting disorders across the United States. This fellowship should include a didactic portion, advocacy within the community, mentorship with experienced APPs and regular webinar-based case studies to review current trends in care. This survey is a call to action to begin standardised education programs for the advanced practice role.

Keywords: *Haemophilia Treatment Centre, Advanced Practice Registered Nurse, Advanced Practice Providers, Roles & Responsibilities, Educational Barriers, Salary Comparison, Practice Patterns, Nursing Fellowship*

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The life expectancy of a person with haemophilia (PWH) was only 20 years in 1960, but is now almost the same as the national average^[1]. Part of this improvement is due to diagnostic and treatment advances, as well as the expertise of those providing care to this

population. Since 1966 it has been recognised that the management of haemophilia and other bleeding disorders requires expertise and input from a variety of disciplines ^[2-5].

Early studies verified that care based at a haemophilia treatment centre (HTC) drastically improved many haemophilia-related physical and economic outcomes ^[5-6]. The core HTC team historically consisted of a physician, social worker, physical therapist and nurse. Over time, the core team has expanded to include advanced practice providers (APPs), specifically nurse practitioners (NPs) and physician assistants (PAs). This evolution has been partly fuelled by the shortage of trained haematologists ^[8-11]. Consistent with the Institute of Medicine's (IOM) concept of team-based care, the HTC team focuses on collaboration to provide coordinated, high quality and patient-centred care ^[7]. As the intricacies of caring for those with bleeding disorders increases, it has become more difficult to find haematologists who are interested in subspecialising in bleeding disorders, leading to medical staffing issues at many HTCs across the United States ^[8-11]. Where there is a gap, APPs have filled that role ^[12,13]. Both NPs and nurses have a larger role in the business management and funding of HTCs, with funding coming through multiple sources including federal and state grants, direct billing for services rendered and, in some cases, program income generated through 340B pharmacy programs ^[14].

The Nursing Role and Responsibilities

In the United States, registered nurses typically have an associates or bachelor's degree in nursing. NPs are advanced practice registered nurses (APRNs) with a master's degree or doctorate in nursing, with advanced clinical training and expertise in diagnosing and treating health conditions, including pharmacology to prescribe medications, that prepare them to practice in multiple settings. NPs are licensed in all states and the District of Columbia, practicing autonomously and in collaboration with other healthcare professionals under the rules and regulations of the state in which they are licensed ^[15]. Physician assistants (PAs) complete a postgraduate program based on the medical model, usually leading to a master's degree, which also focuses on clinical training and expertise in diagnosing and treating health conditions, including prescribing medications ^[16].

US HTC nurses provide their expertise in direct patient care, education, advocacy, research and coordination of the entire HTC program. They also teach home infusion, thus increasing independence

and reducing delays in bleed management. The HTC nurse is often the primary point of contact for patients and families; evaluation and treatment is expedited when calls are triaged by an experienced haemophilia nurse ^[17]. While expert haemophilia nurses play an invaluable role in improving outcomes, little has been written about how they formally develop this expertise, the differentiation between the nursing roles and the APP role, and how their ongoing education is supported. In 2015, the European Association of Haemophilia and Allied Disorders (EAHAD) Nurses' Committee developed a curriculum to standardise and benchmark haemophilia nursing care, based on a survey distributed to haemophilia nurses across Europe ^[18-19]. There are no similar studies within the United States HTC system.

Nurses comprise one of the largest components of HTC staffing, as evidenced by an inquiry into the Center for Disease Control (CDC) staff directory ^[20]. Multiple opportunities are available to receive specialised training in the management of bleeding disorders through programs such as the Partners Program™, Partners PRN™, and the Hemophilia of Georgia New Nurses Training Program ^[21]. However, there are very limited advanced training opportunities for APPs that support their specialised, advanced practice. Continuing education (CE) requirements vary from state to state, between professions (NPs vs. PAs) and between levels of professions (nurses vs. NPs) ^[22-23].

While, in reality, APPs practice similarly on a day-to-day basis, their education (academic and clinical) and scope of practice is different ^[23]. Scope of practice varies from state to state. NPs are educated in the nursing and medical model, while PAs are educated solely in the medical model. Anecdotally, in HTCs, it is felt that APPs are trained by medical directors in a non-standardised fashion. Throughout this manuscript, PAs will be classified with NPs as APPs for ease of classification, with the above understanding noted. As APPs are filling the specialty physician void, there is recognition of a need to establish training programs (fellowships) to successfully acclimatise the APP to their new role ^[24-28]. Additionally, there are a number of new products being investigated and licensed which will refine the focus on personalised treatment. This will require even the most experienced haemophilia nurses to expand their knowledge base ^[29].

Aims

The primary aims of this study are to describe:

- the demographics of all nurses within the HTC community

- the roles and responsibilities of APPs within the HTC community
- the advanced training received to prepare these providers for their positions and support for development of an APP fellowship program
- the barriers experienced by APPs to practicing in a subspecialty practice.

METHODS

Study Design

The study is based on a one-time convenience online survey. A survey of this type had never been attempted in the US HTC nursing community; therefore, there was no opportunity to utilise a previous tool. The authors reviewed previous APRN benchmarking surveys from the American Association of Nurse Practitioners (AANP) and formulated a SurveyMonkey™ questionnaire based on these surveys, as well as the authors' experiences/history and known issues within the community. The study was approved by the Munson Medical Center Institutional Review Board (IRB). Data was analysed using statistical tools through SurveyMonkey™ [30].

Recruitment Methods

Participants were HTC-employed registered nurses (RNs), APRNs and PAs identified through the NHF Nursing Work Group (NWG), CDC Bleeding Disorders Directory [20] and the mailing list for the Partners in Bleeding Disorders Education Program [21]. The eight ATHN regional coordinators were surveyed to verify that the list of nurses within their region was complete. A total of 438 potential participants were identified.

Survey

In March 2014, an introductory letter was emailed to participants alerting them to the forthcoming uncompensated survey. Six weekly reminders were emailed to those who did not complete their survey, with the option to opt out of further emails. No personal health information was collected.

Table 1: Age distribution of all HTC respondents N=168

18-30 yrs	7%
31-40 yrs	18%
41-50 yrs	25%
51-60 yrs	38%
61-70 yrs	12%
70 yrs	1%

Overall Results

The survey was sent to 438 participants. The response rate was 42%, with a total of 186 respondents (%; n): RNs 71% (132), APRN-CNS 1% (2), APRN-NPs 26% (49), PAs 2% (3). The majority held a Bachelor's Degree in Nursing (BSN) (42%; 78), followed by a Masters in Nursing (MSN) (34%; 63), Associates Degree in Nursing (ADN) (14%; 26), Diploma (9%; 16) and Doctorate (2%; 3). Of the 168 complete surveys, 38% (63) were in the 51-60 age group (see Table 1), 95% (159) female, 90% (151) white, 84% (141) working full-time, and 44% (74) held some type of national certification, most through the American Nurses Credentialing Center (ANCC). While 15% (26) of respondents did not have continuing education (CE) requirements within their state for licensure, 13% (21) had CE requirements for pain and 23% (38) had pharmacology CE requirements for continued state nursing licensure.

Although 65% (109) had more than 20 years of healthcare experience, 42% (70) had less than 5 years' experience within the HTC system (Table 2). The distribution of respondents across all sizes of HTCs was fairly equal (>401 patients, 33% (56); 251-400 patients, 25% (43); 100-250 patients, 31% (52); <100 patients, 10% (17)), with the majority representing teaching institutions (74%; 24), treating the lifespan population (61%; 103), and both bleeding and thrombophilia disorders (73%; 122). The respondents' HTCs funded the following positions: RN (65%; 110), data manager (57%; 96), research nurse (48%; 78) and NP (43%; 73). 56% (94) of respondents have no administrative duties in their job descriptions. The majority did not have protected time for any specific activities (62%; 104). Where there was protected time, this was specifically for education (31%; 52), administrative duties (16%; 27), research (15%; 25), advocacy (10%; 16) and publishing (3%; 5).

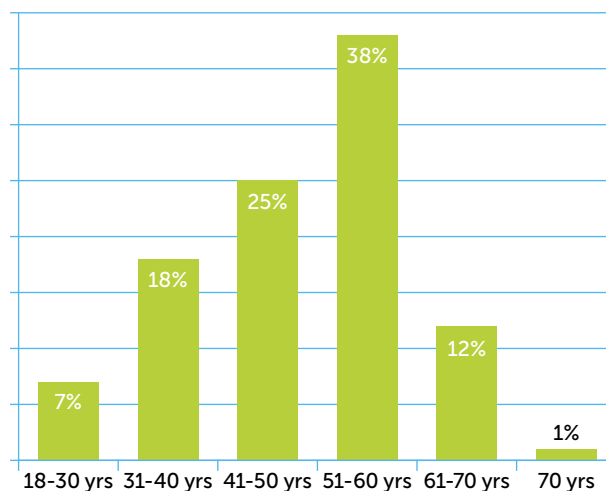


Figure 1: Age distribution of all HTC respondents N=168

Table 2: Years of experience in healthcare compared to years of experience in HTC

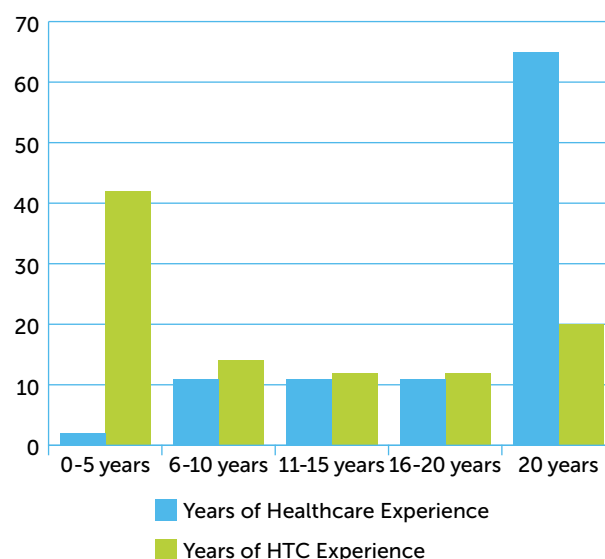
	YEARS OF HEALTHCARE EXPERIENCE	YEARS OF HTC EXPERIENCE
0-5 years	2%	42%
6-10 years	11%	14%
11-15 years	11%	12%
16-20 years	11%	12%
20 years	65%	20%
Total	168	168

Despite the institutional restrictions experienced by 45% (76) of the respondents on the number or frequency of educational activities/development programs they could attend, a variety of training opportunities prepared respondents for their nursing HTC roles, including onsite preceptorship with an experienced HTC nurse (58%; 98), the Partners Program™ (55; 93), onsite preceptorship with a physician (40%; 67), the New Nurses Training Program in Atlanta, GA (32%; 54), online training through Partners PRN™ (20%; 34), industry-sponsored shadow program (7%; 11), and/or a mentor program (3%; 5). The top six ways HTC nurses become aware of important conferences to attend, working groups to participate in, or journals/articles to read were through their nursing colleagues (70%; 117), their regional coordinator (52%; 87), their physician colleagues (51%; 86), their regional colleagues (29%; 49), other staff members (29%; 48), and/or pharmaceutical representatives (28%; 47).

Respondents had minimal publishing experience, with 73% (123) never having published. Some published as the supporting author (24%; 40), first author (8%; 14) or sole author (2%; 4). Nearly half (44%; 75) have never presented at an educational meeting. Of those who have presented, 34% (57) presented at local meeting, 29% (49) presented at NHF and/or other professional meetings, 26% (44) presented at Chapter meetings and/or regional meetings, 21% (13) are on pharmaceutical speakers' bureaus, 11% (19) presented on webinars, and 10% (17) presented internationally at the World Federation of Hemophilia (WFH) or International Society on Thrombosis and Haemostasis, Inc. (ISTH).

In the US, many HTCs receive revenue from the sale of factor concentrate to their patients through a pharmacy program. Only 13% (22) of respondents' HTCs did not have a pharmacy program. In those HTCs with a pharmacy program, 47% (79) of respondents had no involvement. Of those who were involved, 15% (25) had input as to where revenues were utilised, 14% (24)

Figure 2: Years of experience in healthcare compared to years of experience in HTCs



had input on expenses of the program, and 20% (33) were responsible for growth of the program.

Respondents were asked about compensation and benefits based upon a full-time equivalent position. Most were in the \$81-\$90K income range 19% (32), followed by \$61-70K and \$71-80K 17% (28 each), \$51-60K 13% (22), \$91-100K 12% (20), \$101-110K 10% (17), \$121-130K 4% (7), <\$50K and \$111-120K 3% (5), >\$141K 2% (3), \$131-140K 1% (1).

When asked about benefits, 96% (162) received vacation, 86% (147) received health insurance, 76% (128) received retirement and travel to educational meetings/conferences, 66% (111) received CE reimbursement for professional development and conferences, 49% (83) received tuition reimbursement, 42% (71) received malpractice insurance coverage, 32% (53) received a pension, 24% (41) received reimbursement for their licensure/controlled drug substance certification (also known as Drug Enforcement Agency (DEA) certification), 20% (33) received reimbursement for professional association memberships, 11% (18) received bonus incentives, 7% (10) received on-call pay, and 4% (7) received reimbursement for moving expenses.

Advanced Practice Results

55 participants identified themselves as APRNs (nurse practitioners (NPs)/clinical nurse specialists (CNS)) or PAs. These providers were grouped together as APPs, but only 50 answered questions specific to their advanced practice, including whether they prescribed and what, whether they had a DEA license (72%; 36) and whether they maintained this in multiple states (12%;

6). Most APPs (58%; 29) were required by their states to have a collaborative agreement with a physician to prescribe medications, but 36% (18) practiced in states that allowed independent prescriptive authority.

Of the 50 prescribers, 94% (47) prescribed clotting factor, 76% (38) prescribed antithrombotic medications, 68% (34) prescribed Schedule III medications, 60% (30) prescribed Schedule II medications, and 58% (29) prescribed primary care non-scheduled medications, such as statins and hypertensive medications.

When asked to divide the percentage of their responsibilities as an APP, 50% of time was spent on direct patient care, followed by 17% telephone triage, 14% administrative, 8% research, 7% staff/provider education/precepting, 6% community events (camp/family meeting, etc.), 5% pharmacy program and 4% advocacy. APPs evaluate and manage patients independently, seeing them without a physician present and making treatment decisions, mostly for acute events (78%; 39) and follow-up visits (74%; 37). They also independently evaluate new patients (40%; 20) and inpatients (28%; 14). Only 14% (7) responded that they do not see/evaluate patients and make treatment decisions independently.

Answering calls from patients and families after hours is referred to as "taking call" or "being on-call". Most APPs (74%; 37) responded that they do not take any call for their practice. Of those who do take call, 12% (6) take all call, 12% (6) take outpatient call only, and 2% (1) take inpatient only call. When taking call, 75% (9) are on-call less than 15 days per month, with 25% (3) on-call 16-30 days per month. Ten respondents reported receiving on-call pay as a benefit. Many APPs reported having additional responsibilities, including inpatient service (74%; 35) and performing procedures including, but not limited, to bone marrow aspirations (34%; 16). They are also called on to share their advanced level expertise by participating on advisory boards and committees, both within their institution (28%; 13) and outside their HTC (43%; 20).

Most APPs can bill insurance payers independently. In the US, a National Provider Identification (NPI) number is required to bill for services and to identify all providers^[30]. APPs reported that they had provider numbers under their own names, including state and national insurance programs such as Medicaid (77%; 36) and Medicare (57%; 27). The majority billed under their own NPI (70%; 33). It was evenly divided as to whether metrics were used to measure productivity at their institution (40%; 19 each).

When asked about monetary compensation at the time of accepting their position as an APP, 38% (18)

of NPs received additional compensation for previous experience as a RN, while 26% (12) only received compensation for previous experience as an NP and 38% (18) did not receive any additional compensation for previous experience of any kind. Those with a doctorate did not receive additional compensation for their higher degree. Sign-on bonuses were rare (6%; 3).

DISCUSSION

Demographics and Roles of RNs/APRNs/PAs Within the HTC Community

Multidisciplinary team (MDT) care, as provided in the HTC model, is a team-based systems approach to providing healthcare delivery, through communicated care, coordinated information sharing, and cooperative partnerships of various healthcare professionals, patients and their families. With the establishment of the HTC network in the 1970s, the MDT model was adopted with demonstrated overall improvements for patients with haemophilia^[4]. The US Institute of Medicine (IOM) has stated that the concept of team-based care is "the provision of health services to individuals, families, and/or their communities by at least two health providers who work collaboratively, to the extent preferred by each patient. The purpose of Team Based Care is to provide coordinated, high quality, and patient-centred care"^[7]. While nursing practice is at the foundation of the HTC MDT and exemplifies the essential characteristics of communicated, coordinated and cooperative care that is required in a team-based healthcare approach, there has not been a detailed description of the demographics or roles of nurses in the US HTC setting.

This survey revealed an aging nursing population, with over 50% of the respondents over the age of 50, experienced in healthcare but newer to the field of bleeding disorders. They were also highly educated, with the majority holding at least a baccalaureate degree and almost half with national board certification. Involvement in advisory boards and committees reflects the clinical expertise of the group. The practice patterns of the nurses were not surveyed in depth. The practice patterns of the APPs who responded to this survey consisted of mostly clinical roles at teaching institutions specialising in both bleeding and clotting disorders, with various roles within an HTC described as direct patient care, educator, research coordinator, program coordinator, administrator and manager. Both roles (nurse and APP) are necessary for the future of comprehensive care in the HTC setting, with distinctly different responsibilities.

Salaries and compensation varied based on education level, years of experience and institutional benefit packages. There was little relationship between years at the HTC and salary. Those with less than five years' experience were found in all salary ranges, as were those with more than 20 years' experience at the HTC. Compensation increased in line with educational level, with 63% of master's prepared nurses and 100% of doctoral prepared nurses receiving more than US\$100,000 per year, 67% of bachelor's prepared nurses receiving between US\$61-90,000 per year, and 65% of associate prepared nurses receiving less than US\$70,000 per year.

Advanced Training Received to Prepare APPs for their Positions

Knowledge and information is acquired through continued education, on-the-job learning, and mentorship of experienced practitioners. State licensure requires continuing education, with a growing focus in pharmacology and pain management, demonstrating the need for standardised programs. This survey revealed that the specialised education of HTC nurses is an uncoordinated mix of on-site institution-specific training/mentorship by a physician/nurse, and through one particular curriculum-based program, the Medical and Scientific Advisory Council (MASAC)-endorsed Partners in Bleeding Disorders Education™, in addition to other symposia^[21]. The Partners program objectives are "to describe the pathophysiology of haemophilia, its underlying genetics, basic treatments, and possible complications"^[32].

Sources of information for training come from nursing colleagues, regional coordinators and HTC physicians. The educational preparation and training of the APP was focused more on the medical model and generally delivered by the on-site physician, with no standardised curriculum. APPs reported minimal involvement in a mentoring program.

Support for Advanced Practice Nursing

In the IOM's 2010 landmark publication, *The Future of Nursing*, significant recommendations were outlined that propelled the profession of nursing, and the advanced practice role specifically, to the forefront in shaping the delivery of healthcare in the United States^[7]. Historically, nurses have been the frontline for patient contact, and in the HTC model are at its core. The IOM document recognises and supports and recognises the need for the unique skills presented by the profession

to advance the responsibilities and roles of the nurse. Four key messages were identified:

- Barriers to nursing practice need to be removed to enable nurses to practice to the fullest extent of education
- Improved seamless educational systems are needed to allow for higher levels of nursing education
- Full partnership between nurses and physicians should be allowed
- Data collection and information infrastructure must be improved to create effective workforce planning and policy making.

This survey demonstrates the active utilisation of APPs in the comprehensive care model of the HTC. The specific APP role was reported to include direct patient care, phone triage, research and administrative responsibilities. Under the Title 21 US Code Controlled Substance Act, any person in the US who dispenses a controlled substance must register with the government and receive a Controlled Drug Substance (CDS) number and Drug Enforcement Agency (DEA) number^[33]. Most APPs reported having a CDS number and state licensure from the DEA in at least one state, with either independent prescriptive authority or delegated authority through a collaborative agreement with a physician. Medications commonly prescribed included clotting factor concentrates, antithrombotic medications and Schedule II-V medications, reflecting the needs of the populations served. Most APPs report the availability of a physician on site, but some report autonomous practice^[12]. The majority report independent patient management of acute events and follow-up visits, and to a lesser extent, new patient and inpatient visits. Over 70% of APPs bill independently. Only half stated that their productivity is measured by billable encounters.

One role of the APP is research, which is critical in furthering evidence-based nursing practice^[26]. Over half of respondents report having no protected time to conduct or participate in nursing research. Those with protected time are involved in research and publishing, ranging from sole authorship to supporting authors and involvement in peer review journals. A focus on evidence-based research will be critical as nurses and APPs within the HTC community improve patient care and outcomes.

Limitations

This was an anonymous convenience study which provided a snapshot of the HTC nursing landscape at a point in time. As healthcare rapidly evolves, roles

and responsibilities evolve quickly, as does the need to monitor and identify trends and barriers. The survey did not define role responsibilities for the US HTC nurse. Future surveys will define and delineate that role more precisely.

Conclusion

The subspecialty of bleeding disorders nursing requires specialised knowledge, skill and independent decision-making. In our survey, over a third of the nurses will reach retirement age in the next 10-15 years, thus increasing the urgency of efforts to create a standardised approach toward education, with the goal of supporting recruitment and retention.

One challenge to education standardisation is that, unlike other subspecialty nursing areas, there is not an independent nursing society guiding the curriculum. Without this, progress toward standardisation of education is slow and sometimes disjointed. Over half of the nurses surveyed did not report restriction on educational or developmental programs as a barrier, indicating that participation in additional educational initiatives would be supported.

A barrier is the small number of HTC nurses compared to other subspecialties, such as diabetes or oncology. The Hemostasis Nursing board certification, which became available in December 2015, is a step towards the standardisation of competencies. The curriculum developed by the EAHAD Nurses' Committee would also be an excellent resource for the US nurses to use as a template ^[19]. Further development of an APP fellowship program would standardise the care and treatment of those with bleeding and clotting disorders across the United States. This fellowship should be developed by experienced APPs currently practicing in the field, and include a didactic portion to include differential diagnosis, diagnostic testing and tools, assessment, treatment options, evaluation, research opportunities and patient outcome studies. Advocacy within the community is also important, including advocacy for the consumer, the community and for nursing. Mentorship with other more experienced APRNs would be advantageous, as would regular webinar-based case studies to review current trends in care.

There is high demand for sub-specialised care for the bleeding disorders community. To continue providing the high level of care required by this population, further standardised education will be required for the APP. This survey is a call to action

to begin standardised education programs for the advanced practice role.

What is a nurse-led service?

A discussion paper

The terms 'nurse-led service' and 'nurse-led care' are often used, but are frequently not well defined. As health care delivery evolves across the world and struggles to cope with changes in medical care and with the rising number of people living longer with long term conditions, it is frequently suggested that more care should be delivered and coordinated by nurses who have the most day-to-day contact with affected individuals and their families. This paper addresses the notion of modern 'nurse-led' care in the 21st century, with a focus on haemophilia. Haemophilia is one specialty in which totally nurse-led and delivered care could become a reality, there is already evidence from both developing and developed countries of nurses providing excellent and innovative haemophilia care.

Keywords: Nurse, nurse-led, haemophilia

The terms 'nurse-led service' and 'nurse-led care' are often used, but what do we mean by them? Can nurses truly lead services for individuals or is that the remit of medical staff who can investigate, diagnose, prescribe and treat? Historically nurses worked alongside doctors delivering care stipulated by doctors. Florence Nightingale changed that, challenging assumptions about medically ordered care and delivering nursing care, which was both compassionate and collected evidence of outcomes. Nursing has come a long way since then, and many things have changed. Wherever we implement change we do it for the benefit of those patients and families that we care for, to do that as

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best as we can we need evidence of our abilities and the impact our care has on patient and their families.

It is frequently suggested that the role of nurses will become increasingly important in the future delivery of care for people with haemophilia. Paul Giangrande former vice-president (medical) of the World Federation of Hemophilia and current chairman of the medical advisory board of the European Haemophilia Consortium, is on record as saying: "Nurses are an extremely valuable resource in the care of haemophilia patients and they increasingly take on more responsibilities, including treatment of acute bleeds, organising outpatient review clinics, training parents and children in venepuncture and prophylaxis, and prescribing factor concentrates and other medicines,"^[1].

In this paper we address the notion of 'nurse-led' care in the 21st century, where we are today and where we are, or could be going.

What do we mean by 'nurse-led'?

In the absence of a formal definition of 'nurse-led', investigators have applied the term to various service models in which nurses have a leadership or supervisory role or practise without direct supervision

Table 1. Models of nurse-led services differentiated by degree of autonomy

A highly qualified nurse- e.g. an Advanced Nurse Practitioner (ANP) - may lead and be responsible for a service ^[2]	Problems faced by a transitional care intervention for cognitively impaired older adults and their caregivers lead by ANPs
Nurses may be part of a nurse-led service and practise under the leadership of a highly qualified nurse or have service-specific training ^[3]	Pilot study of a tailored, person-centred stroke self-management support intervention developed by specifically trained stroke nurses and stroke survivors
Nurses with no advanced qualification may deliver a service in remote or underpopulated areas independent of day-to-day supervision ^[4]	Médecins Sans Frontiere and the South African government have implemented a nurse-based, doctor-supported model of care to combat the AIDS epidemic and increase access to antiretroviral treatment (ART). The model decentralizes administration of ART for HIV positive patients through nurse-initiated and -managed ART
Nurses may deliver a service under a patient group direction or equivalent ^[5]	Patients who underwent resection for colorectal cancer were followed up by a nurse specialist according to a protocol determined by the colorectal surgeons in the unit. Detection rates for recurrent or metastatic disease were comparable to consultant follow-up. A nurse-led clinic provides the benefits of follow-up without overwhelming the consultant colorectal surgical clinic practice.

by another health professional. The differentiating factor is the extent to which nurses practise autonomously (Table 1) ^[2-5]. Even within a nation and a single specialty, there may be a range of activities undertaken by nurses, any of which may be considered – perhaps especially locally – to be meet the definition of nurse-led. The characteristics of a nurse-led service have been defined ^[6] by a set of activities:

- direct referral mechanism
- assessment and technical skills
- freedom to initiate diagnostic tests
- prescription (to protocol) of medications
- increased autonomy and scope for decision making
- discharge.

These authors suggested the extent to which nurses carry out activities independently of other health professionals, notably doctors, can be grouped into three levels ‘depending on the expertise of the nurse and the level of trust from the consultant physician/ surgeon’ ^[7]. This approach was applied to a review of 88 nurse-led cancer clinics in the west of Scotland, demonstrating wide variation in the nurses’ roles at each clinic (Figure 1) and differences in levels of practise (Table 2) ^[7]. The authors noted that the sustainability of these nurse-led clinics was influenced by practical issues such as availability of suitably trained nurses and adequate administrative support, both of which may reflect managerial attitudes that undervalue the nurses’ expertise and undermine the extent to which practice autonomy can be achieved. Their recommendations

for expanding nurse-led services included establishing a framework, protocol template and audit guidance; ensuring suitable organisational support; and developing training and research.

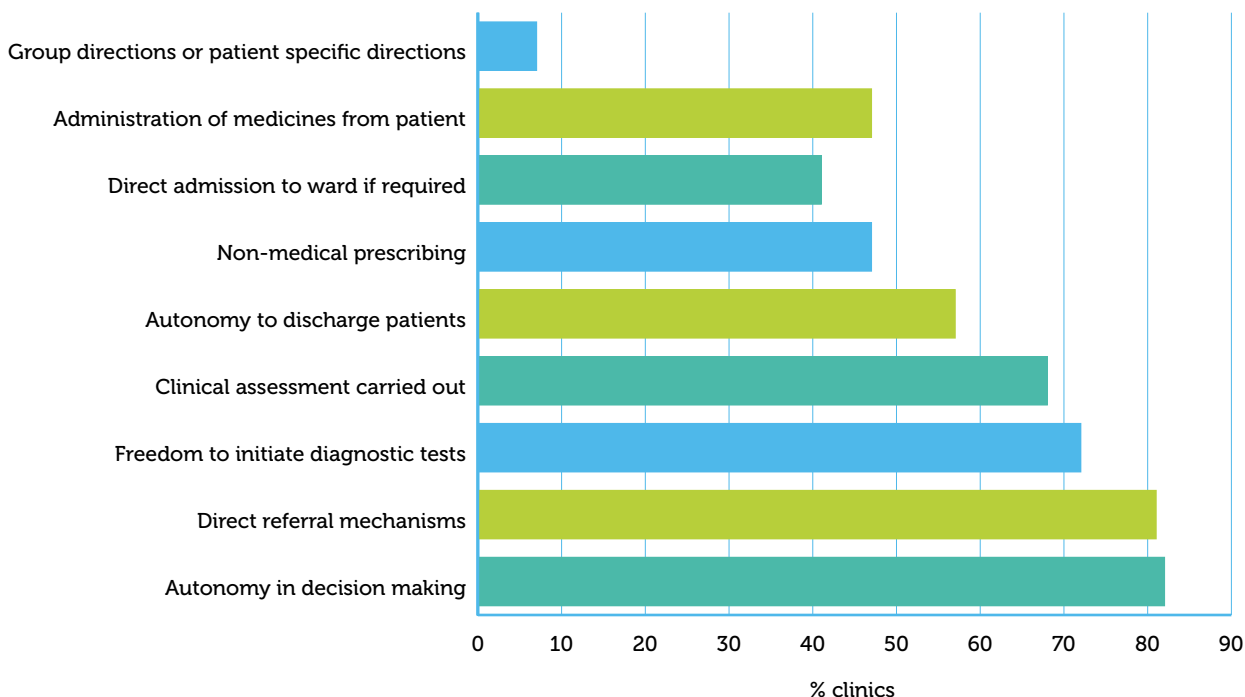
In which conditions are services largely nurse-led?

Nurse-led services are established across most (if not all) specialties. In the UK, some services in some localities are largely delivered by nurses – for example, the management of cystic fibrosis, sickle cell anaemia, hepatitis C, renal disease, congenital heart disease, juvenile rheumatoid arthritis, type 1 diabetes, haemophilia – though in some instances the service is available only from a specialist centre. There is no published evidence to quantify differences between specialties in the proportion of services that are nurse-led.

Haemophilia is one example of a specialty in which nurses in some centres deliver the vast majority of services. One survey of 94 haemophilia nurses in 14 European countries found that most were active across the spectrum of service provision: almost all were involved in treatment delivery and direct patient contact, with the majority also providing education, research and service coordination ^[8].

Elsewhere, nurse-led interventions in many different specialties may form an autonomous part of an interdisciplinary service – for example, delivering some aspects of management such as blood pressure measurement or medication monitoring. The service may be hands-on and involve direct patient contact

Figure 1. Activities carried out in nurse-led cancer clinics, Scotland ^[7]



or it may be managerial: a study from The Netherlands describes how practice nurses act as case managers and are responsible for planning and monitoring care and encouraging cooperation between the disciplines that deliver it ^[9]. This is an example of a service in which nurses carry out what could be described as a traditional leadership role but do not practise clinical autonomy. Conversely supportive roles, such as counselling, are more likely to become nurse led in response to patient need. A genetic counselling service

for haemophilia in Ireland demonstrated improved client satisfaction and education following attendance at a nurse delivered genetic counselling and testing clinic ^[10].

There is good evidence to support the case for nurse-led services across different specialties. A review of 32 systematic reviews of nurse-led services in OECD countries (17 from the UK) found consistent evidence from comparative studies that nurse-led care was at least as good as traditional medical-led service models

Table 2. Levels of practice in nurse-led cancer clinics, Scotland ^[7]

ACTIVITY		LEVEL OF PRACTICE	
Assessment	Holistic nursing assessment (verbal) including symptom assessment	Holistic assessment and physical examination/ clinical assessment focusing only on tumour group	Holistic assessment with full physical examination/clinical assessment
Referral method	Internal from doctor	Internal from doctor or other discipline	External and internal sources, any type
Diagnostic testing/ consultation	Initiated by doctor	Joint with discussion	Independent decision/order
Prescription	No prescribing	Within clear protocols, for example, patient group directions	Non-medical prescribing
Decision-making	With permission	In discussion	Autonomous
Discharge	Refer back to doctor	Discharges from nurse-led service	Discharges from service/ hospital and/or into primary care

Table 3. Characteristics of a condition and its treatment that make it amenable to nurse-led care

CHARACTERISTIC	EXAMPLES
The condition is chronic and requires ongoing intervention	drug dependency, heart failure, COPD, diabetes
The condition is acute and does not require ongoing medical intervention	follow-up of transient ischaemic attack
The intervention is preventative	immunisation
Management is deliverable by a nurse with suitable competency	
Management includes 'traditional' nursing skills	
Management requires regular monitoring, adjustments to treatment and ongoing education	asthma, diabetes
Patients benefit from the superior 'person' skills of nurses	
Doctors can't be bothered or don't have the time, or it's cheaper for nurses to do it	lipid level monitoring, wellbeing clinic
Treatment is technically too difficult for some or all patients or carers to administer, or requires support	at-home infusion of enzyme replacement therapy
Treatment requires a high degree of personalisation that may change over time	insulin therapy, factor replacement therapy
Treatment decisions depend on an holistic assessment of the patient's current needs via regular one to one consultations	cystic fibrosis

in mental health care and the management of long term conditions^[11]. There was little evidence that it improved clinical outcomes compared with usual care models and no evidence of cost effectiveness but this may be a consequence of the difficulty of carrying out such research rather than the result of it.

What is it about these conditions that they lend themselves towards being provided by nurse led services?

There are likely to be multiple reasons for establishing a nurse-led service. There are features of some conditions and their treatment that make them amenable to nurse-led care (Table 3). Some might reflect 'traditional' nursing roles, such as the physical aspects of care or psychosocial support; others demand specific advanced training to help patients with complex tasks.

But, in addition to the 'pull factor', there is usually a 'push factor'. In today's NHS and many other health services, the push is likely to come from pressure on resources. If there are not enough doctors (or other disciplines) to meet clinical need or not enough money to pay them, nurse-led services can be an attractive option. There are more nurses than doctors (though hardly a surplus) and for some time the political agenda in some countries has favoured a shift in funding and facilities from the hospital sector (with its stronger hierarchies) to community care, funded by savings from removing established services. The nursing profession

also benefits from its foresight in embracing continuing professional development and developing governance, because it now has access to well-established training and enforcement of standards of practice.

Resource pressures will strongly influence the nature of a new nurse-led service but they need not stifle innovation. Different funding models can serve a common cause in very different settings, as a description of three nurse-led services in the Philippines, Kenya and Tanzania shows^[12]. In these cases, local circumstances dictated the possible business models and a government-funded cooperative, a nurse-led social franchise and a midwife-led network of maternity centres were all successful in meeting their aims. The characteristics of a medical condition are therefore important but other factors can determine the success or otherwise of a nurse-led service.

Geography can also be a factor in developed economies. In Australia, nurse practitioners were established to plug gaps in primary care provision in remote and rural areas but subsequently strengthened other aspects of health care^[13]. And those nurse-led services are not confined to specialties that might be perceived as mainstream: a rural nurse-led clinic for women with sexual dysfunction 'confirmed the value of an innovative approach to managing female sexual dysfunction in a rural area with workforce shortages and limited health services'^[14]. In the UK, one of the most crowded countries in Europe, a nurse-led

specialist neurology service was established to ensure health care remained patient-focused in Argyll and Bute, an area of low population and sometimes difficult transport ^[15].

There are clearly obstacles to introducing a nurse-led service where there has been no prior provision but there are also barriers to overcoming the historical norms of service provision. It is a fact that, even in developed economies, 21st century health care can be dominated by the medical profession. Building a new service under the control of a non-medical professional is potentially a challenge and the accession of the medical profession is often necessary for progress. In a recent appraisal of care provision for long term conditions in Europe ^[16, 17] it was stated:

'The use of nurses in care delivery and coordination is common in systems that have a tradition in multidisciplinary team working... Examples include nurse-led clinics and nurse led case management as established in countries such as England, Italy and the Netherlands. Conversely, the introduction of nurse-led approaches in primary care has remained challenging in systems where primary care is traditionally provided by doctors in solo practice with few support staff.'

'However, there are moves in these countries towards enhanced functions of nurses in care coordination or case management, as, for example, in Denmark, France and Lithuania. Countries are also seeking to strengthen the role of nurses in providing patient self-management support or the delivery of selected medical tasks, although most often such tasks have remained under the supervision of the GP or family physician, such as in Austria, France and Germany.'

An analysis of 27 studies of the perceptions of nurse and medical practitioners working in primary health care published between 1990 and 2012 found that the most frequently cited barrier to collaboration was the lack of awareness by doctors of what nurse practitioners could offer ^[18]. Collaboration 'worked well' when nurses assumed responsibility for routine aspects of care but this did not necessarily lighten the medical workload because nurses who did not have full autonomy still had to consult a doctor about some aspects of management. Doctors complained of losing control and nurses saw hierarchies and power struggles. Trust between nurse and medical practitioners was the key to success.

It is therefore apparent that, even in advanced economies, the health care setting in which a nurse-led service is delivered is an important factor in its

success. This includes the historical, structural and organisational context in which management of the condition is delivered as much as the nature of the medical interventions themselves.

Government policy

Introducing change to a highly structured publicly funded health service will be difficult if government policy is not at least facilitative and preferably supportive. Table 4 lists the activities of nurses associated with nurse-led services in European countries, as identified by a 2015 review carried out under the auspices of the World Health Organisation ^[19]. It shows wide variation in clinical activity and differences in the extent to which regulation permits nurses to expand their role beyond a traditional model.

A comparison of nurse-led services in the UK, New Zealand and Australia concluded that financially incentivising GPs via the Quality Outcomes Framework (QOF) and consequent improvements in clinical governance was the driver for developing nurse-led services in the UK ^[20]. Services were less developed in the comparator countries, which were characterised by lack of financial incentives, health service policy and rivalry with the medical profession. Government policy had prepared the ground with the 1990 General Medical Services contract for doctors, which rewarded GPs who achieved targets for immunisation and cervical cytology that were best achieved by employing nurses to do the work ^[21]. QOF payments are made to practices rather than individual doctors, making employment of nurses easier.

This is a striking example of the potential power of official support because nurse practitioners were officially established in Australia in 2000 ^[13]. In the UK, nurse-led services have long been championed by a Government attempting to meet demand for NHS services within tight budget constraints ^[22].

The unique funding position of the NHS probably accounts for the exceptional urgency with which the UK Government has acted but this does not mean that other countries have stood still. In Italy, 'The main aim of legislation for the nursing profession over the last decade has been to provide nurses with a more autonomous and active role and to give them new responsibilities so that this important profession is no longer seen as an auxiliary one ...' ^[19] Germany introduced legislation in 2008 to enable doctors to delegate some aspects of the care of patients with chronic disease to nonmedical staff

Table 4. Provision of nurse-led services in European states, 2015 ^[19]

Austria	Task substitutions such as nurse-led diabetes clinics or nurse-led health education do not occur in primary care.
Belgium	-
Bulgaria	'...new care arrangements – such as task substitution with nurses – do not occur in Bulgaria.' Nurses are not involved in caring for diabetics, for example, or providing health education. This is due to the lack of targeted education in this area, as well as specialized training for nurses working in primary care.
Cyprus	-
Czech Republic	Nurses do not lead diabetes clinics or perform other forms of health education.
Denmark	'Patients have direct access to ophthalmologists, ENT specialists, cardiologists, neurologists and surgeons, and only need a referral to visit GP practice nurses, specialist nurses, home care nurses, dentists, midwives, occupational therapists'.
Estonia	Nurse-led activities such as health education or diabetes care are rather uncommon in primary care.
Finland	Nurses are frequently the point of first contact in health centres, and usually provide nurse-led health education. Specific clinics, such as nurse-led diabetes clinics are rarely performed in primary care.
France	Nurse-led substitution of care for health education and prevention is very limited: around 60 ambulatory structures concerning health education and diabetes clinics exist in France. The only medical act ambulatory nurses are able to do without a prescription is seasonal flu vaccination for the target population.
Germany	'A special service for people with specific problems, such as diabetes, is unusual in a German general practice (less than 10%)... All medical professions can directly be accessed by patients with few exceptions... there has been a strong trend towards practices with multidisciplinary cooperation during the last five years... The principal reason for this trend is, above all, a financial incentive...'
Greece	Coordinated and integrated primary care is non-existent in contemporary Greece.
Hungary	Nurse-led care is rare.
Iceland	-
Ireland	'Plans for integrated care services between primary and secondary care have been established for chronic obstructive pulmonary disease, asthma, stroke, acute coronary syndrome, heart failure and diabetes.'
Italy	-
Latvia	Nurse-led activities like health education or diabetes care are quite uncommon in primary care.
Lithuania	-
Luxembourg	Task substitution does not exist in primary care. For example, nurse-led clinics within primary care, for example for patients with diabetes, or to provide health education, do not take place.
Malta	-
Netherlands	It is very common that primary care nurses perform nurse-led diabetes clinics in primary care, or nurse-led health education.
Norway	Nurses form, with GPs, the core of primary care. Their role seems to be health education and traditional nursing services.
Poland	Public has free access to nurses.
Portugal	Nurse-led substitution of care, mainly in health education and prevention, is very common.
Romania	-
Slovakia	It is very uncommon for nurses to run specialist (e.g. diabetic) clinics or conduct health education activities.
Slovenia	Advanced roles for nurses in primary care do not exist... The role of the specialized nurse (e.g. in diabetes care) is not well developed and established, although some work in so-called "health education centres" at the primary care level, some work in polyclinics and some in hospitals.
Spain	Currently, the role of the nurses is expanding and they play a key role in promotion, prevention and follow-up of chronic diseases, as well as involvement in community care and home care... Most of the prevention and health promotion activities, home care and follow-up of chronic diseases are carried out by nurses, who arrange the patients' health care plans together with the GP... In most of the Autonomous Communities, nurses have seen their roles expand and currently they are independent decision-makers in the health care process of their patients.

Sweden	Task substitution, for example through nurse-led diabetes clinics in primary care and nurse-led health education, are very common.
Switzerland	...there is limited access to specialized nurses... Currently there are no primary care nurses in Switzerland.
Turkey	'It is very common for family doctors to work with a re-trained practice nurse who provides several services, including maternal care services, immunizations, or health promotion and education services.'
UK	In recent years there has been increased skill mix in primary care, especially nurse-led chronic disease clinics; between 1995 and 2006, the percentage of consultations conducted by nurses increased from 21% to 34% (England).

as part of a Disease Management Programme^[17]. In the Netherlands, an amendment to the Individual Health Care Professions Act (Wet op de beroepen in de individuele gezondheidszorg) recognised qualifications for clinical nurse specialists that allow them to autonomy in the performance of common and minor medical procedures in preventive, acute, intensive or chronic care^[17]. In the Republic of Ireland, the Government and the National Council for the Professional Development of Nursing and Midwifery created policies ensuring a supportive environment to nurture nurse-led services^[23,24]. The Hospital Authority of Hong Kong, facing growing demand on emergency departments (which, in the absence of primary care, are the first point of contact with health services), established specialised clinics led by advanced nurse practitioners; their role subsequently developed so that nurse specialists are now leading out-patient clinics^[25].

A government's approach to regulation strongly influences how nursing practice develops. A review of governance arrangements for nurse practitioner-level practice in Europe, the United States, Australia and New Zealand concluded that 'Countries with primarily decentralized regulation showed uneven levels of advanced practice, due to the different scope of practice laws by states and the different pace at which change occurred'^[26]. Surprisingly, given the advanced status of nurse practitioners in the United States, progress has been slowed by the separate governance arrangements enacted by the independent states. In Australia, inter-state differences in regulation and endorsement policies created barriers to mobility for nurses and different practice models, increased duplication and raised costs. These problems were tackled by shifting responsibility for governance from states and territories to national level. In the UK, governance is the responsibility of employers and health care providers; this has led to 'large advanced practice variations across and within professional titles, settings and regions'.

What are the skills and competences needed by specialist nurses to allow them to deliver nurse-led services in these conditions?

It is difficult to identify the requirements specifically for providing nurse-led services – if indeed they exist. In the UK in 2014, the potential extended role of nurses was recognised by the Chief Nurse at the Department of Health in the NHS Plan. She identified 10 key roles for nurses: ordering investigations (X-rays/pathology), making and receiving referrals, admitting and discharging patients, managing patient caseloads, running clinics, prescribing medicines, carrying out resuscitation, performing minor surgery, Triaging patients and leading local health service organisation and delivery^[27]. The nurse's role in improving care and outcomes through working together for better patient experience is recognised. In the UK, Advanced Nurse Practitioner (ANP) is probably the minimum competency level necessary to be responsible for a nurse-led service – that is, to exercise professional autonomy – but, as noted, some services described as nurse-led may not require autonomy^[27]. There is also a lack of consistency between countries in the way the terms ANP and Nurse Practitioner are used. Summaries of the roles and qualifications of ANPs or Nurse Practitioners in Europe are available online from International Advanced Practice Nursing at <https://internationalapn.org/europe>. In the UK, ANP competencies published by the Royal College of Nursing (RCN) (Table 5) are intended to support recommendations by the Home Nations^[25, 28-31]. Such clear leadership might be welcomed but the competencies have been criticised as poorly defined and complicated by differences between the Home Nations^[32]. These authors recommend mapping UK competencies to those developed in the United States, a country with more extensive experience of the ANP role^[33].

ANP competencies in the UK^[28], and United States^[33], and Nurse Practitioner competencies in the Netherlands^[34] and Australia^[35] represent

Table 5. Competencies for Advanced Practitioner Nurses, Royal College of Nursing 2012 ^[28]

making professionally autonomous decisions, for which they are accountable
receiving patients with undifferentiated and undiagnosed problems and making an assessment of their health care needs, based on highly-developed nursing knowledge and skills, including skills not usually exercised by nurses, such as physical examination
screening patients for disease risk factors and early signs of illness
making differential diagnoses using decision-making and problem-solving skills
developing with the patient an ongoing nursing care plan for health, with an emphasis on health education and preventative measures
ordering necessary investigations, and providing treatment and care both individually, as part of a team, and through referral to other agencies
having a supportive role in helping people to manage and live with illness
having the authority to admit or discharge patients from their caseload, and refer patients to other health care providers as appropriate
working collaboratively with other health care professionals and disciplines
providing a leadership and consultancy function as required

the high standard of clinical, academic and managerial performance required for professional autonomy. These countries are at the forefront of professional development for nurses. Elsewhere, advanced clinical performance is recognised but not rewarded with autonomy. In Sweden, for example, ANP is a title restricted to graduates of approved education programmes but they cannot practice autonomously ^[36,37]. Competencies aimed specifically at developing advanced skills within haemophilia nursing have been developed in the UK ^[38] and within Europe ^[39] these form a starting block for developing a haemophilia nursing curriculum and expertise within individual nations/geographical regions to improve care delivery to those individuals and families with bleeding disorders.

Conclusions

Health care delivery is changing wherever you are in the world, to cope with changes in medical care, with more people living longer with long term conditions. Much of this care can be delivered and coordinated by nurses who have the most day-to-day contact with affected individuals and their families. Historically nurses have been seen as doctors' assistants, now is the time for us to emerge from the shadows of our historical lamps and let the light of the care that we deliver shine in their own right.

Haemophilia is an area where totally nurse-led and delivered care could become a reality, there is already evidence of nurses from developing to developed countries providing excellent and innovative

haemophilia care. Given the cost-constrained environment in which health care is delivered, if haemophilia nursing is to achieve its full potential it will be necessary for haemophilia nurses to demonstrate the value they offer by evaluating the services they provide and publishing their results.

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