

The role of the nurse in adult congenital heart disease: past, present and future

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Introduction

Congenital heart disease is an abnormality in the structure of the heart that is present from birth. It is the most common birth defect, affecting 0.9% of all live births in western Europe (GBD Congenital Heart Disease Collaborators, 2020). Congenital heart diseases are heterogenous and vary in complexity, management and clinical outcomes, being classified as mild, moderate or severe. Improvements in neonatal screening, as well as surgical and medical advances in the paediatric population, means that today more than 90% of children born with congenital heart disease will survive to adulthood, compared to just 15% in 1945 (Brida and Gatzoulis, 2019). There are now more adults living with congenital heart disease than children, with the adult population expected to increase exponentially until 2050 before plateauing (Baumgartner, 2014).

This article discusses the impact of adult congenital heart disease (ACHD) on patients and healthcare services as well as the role of nurses in the care of ACHD.

Adult congenital heart disease: impact on patients and services

There is no cure for congenital heart disease and any intervention or surgery is palliative. Long-term cardiac and non-cardiac complications of congenital heart disease include:

- Reinterventions (surgical and catheter)
- Heart failure
- Arrhythmias
- Renal impairment
- Plastic bronchitis
- Protein-losing enteropathy
- Liver disease
- Endocarditis
- Pulmonary hypertension
- Thrombo-embolic disease
- Premature death
- Haematological conditions
- Cancer
- Psychosocial distress (Lui et al, 2017; Baumgartner et al, 2021).

The Swiss Adult Congenital Heart Disease Registry demonstrated that 89% of heart failure cases, >80 of arrhythmias, >70% of strokes and myocardial infarctions, and >70% of endocarditis presentations occurred in patients aged over 18 years (Arslani et al, 2018). In a contemporary cohort of adults with congenital heart disease, heart failure was the leading cause of death, accounting for 30% of all deaths in this patient group, with perioperative death accounting for 22% and sudden cardiac death for 20% (Engelings et al, 2016).

In addition to cardiac complications, comorbidities are common. The German ACHD registry demonstrated that 57% of patients aged <40 years had at least one comorbidity, with four or more comorbidities present in around 10% of patients (Maurer et al, 2021). In patients aged >40 years, 78% had one comorbidity and around 20% had more than four; cardiovascular, endocrine and metabolic diseases were the most common comorbidities, with prevalence being twice as common as those aged <40 years. These data highlight the need for long-term cardiovascular risk reduction for this group of patients, who are now living long enough to acquire cardiovascular disease in addition to their congenital heart disease.

In the United States, the annual number of patients hospitalized for ACHD increased by 87% between the periods 1998–2004 and 2004–10 (O’Leary et al, 2013). The median

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number of yearly outpatient appointments for ACHD at the Brompton Hospital in London increased by 285% between 1991–95 and 2006–10 (Kempny et al, 2016). Billett et al (2008) demonstrated that adults and children with congenital heart disease were more likely to have cardiovascular comorbidities, diabetes, renal disease and epilepsy than controls. In addition, they were more likely to use primary care services and require more prescriptions.

Patients with congenital heart disease have high service use and require lifelong care. Cordina et al (2018) provided justification for specialist care for patients with ACHD; compared with patients managed by ACHD specialists, those under general cardiology follow up were less likely to receive guideline-directed care, leading to a higher risk of adverse events. Similar outcomes were presented by Diller et al (2021), who compared specialist ACHD care to follow up in primary care. Specialist care was associated with fewer major complications and increased survival. However, in both studies the authors reported that many patients with ACHD do not receive timely specialist follow up, emphasising the need for optimal systems to promote equitable access to specialist services as the population grows (Cordina et al, 2018; Diller et al, 2021). Therefore, while much work has been done to identify and develop specialist ACHD services and promote research in this area, much more is required (Baumgartner, 2014).

The structure of adult congenital heart disease care

In the UK, the care of adults with congenital heart disease is overseen by specialist commissioning. Centres providing care are designated and structured according to specifications that were set out in the national review of ACHD services in England (NHS England, 2016). There are 11 congenital heart networks within NHS England, which provide a tiered level of care. Level one services offer specialist congenital heart disease surgical care, complex structural intervention and electrophysiology, in addition to specialist cardiology care and assessment. Level two centres offer some simple structural interventional procedures and specialist cardiology review. Level three centres ensure that patients receive as much non-interventional treatment as close to their home as is safe, supported by local ACHD centres. In NHS Scotland, a nationally commissioned service provides level one care to Scotland and supports local care.

NHS England and NHS Scotland published standards for ACHD care (NHS England, 2016; NHS National Services Scotland, 2018). The aim of these standards is to ensure equity of access to long-term follow up with appropriately trained and experienced clinicians. The standards clearly define the staffing specification for each level of specialist centre, including nursing resources. However, the number of ACHD consultants currently employed is approximately one-third of the number required to meet NHS England standards (Crossland et al, 2021). The standards also highlight the need for appropriately-trained nurses in wards, critical care, catheterisation labs and outpatient settings that may encounter patients with ACHD, as well as specialist ACHD nursing roles. The NHS England (2016) standards includes a minimum of five whole-time equivalent ACHD nurse specialists at each level one centre. Again, the numbers currently employed fall short of the number recommended in the standards. NHS Scotland did not state a minimum number of specialist nurses at the level one centre.

The evolution of the role of the nurse in adult congenital heart disease

Canobbio and Day (1994) described the role of the nurse specialist in ACHD as:

- Practitioner
- Coordinator
- Educator
- Patient counsellor
- Consultant
- Researcher.

In 2006, Moons et al (2006) published the results of the Euro Heart Survey on congenital heart disease, specific to nursing roles. This demonstrated that physical examination,

telephone triage, patient education and care coordination were the most common activities undertaken by ACHD nurses. Physical examination at that time consisted mostly of routine observations (blood pressure, heart rate, weight), with 40% of respondents assessing for pitting oedema and <10% undertaking assessment of jugular venous pressure and palpation of the liver. Moons et al (2006) recommended that future ACHD nurses should be educated to Masters' degree level, reflecting the complexity of managing a heterogenous group of conditions. Vernon et al (2011) stated that, in addition to the core skills described by Canobbio and Day (1994), Moons et al (2006) and Kennedy (2008), the role of the ACHD nurse specialist could develop in line with national advanced nursing practice to include clinical assessment, non-medical prescribing and more nurse-led components of the ACHD service.

In 2017, the International Society for Adult Congenital Heart Disease published a position statement detailing the role of the ACHD nurse (Sillman et al, 2017). They listed six domains of the role (Table 1). These domains, along with specialist transition roles, reflect the original roles of the ACHD nurse and the core components of the role today.

What do adult congenital heart disease nurses do in 2022?

Reflecting national inconsistencies in job titles, ACHD nurses can be employed as nurse specialists or nurse practitioners (Leary et al, 2017). While the authors refer to ACHD nurse specialists, they acknowledge the importance of clearly defining each role, as both roles have a place in ACHD services. From eight nurses in 2007, there are now over 80 ACHD nurse specialists and nurse practitioners in the UK (data from a person list of all ACHD nurses accessed by the authors).

The role of the ACHD nurse remains diverse. The structure of the role varies across different centres, but there are core components of the role that are required to meet NHS ACHD standards. The heterogenous and complex nature of ACHD demands that nurses have an in-depth knowledge and understanding to facilitate safe management. Specialist

Domain	Activities
Organisation, coordination and facilitation of care	<ul style="list-style-type: none"> Managing patient calls and triage Coordinating care Liaising with the multidisciplinary team Skilfully managing caseloads
Holistic assessment	<ul style="list-style-type: none"> Carrying out psychological and social assessments
Patient education	<ul style="list-style-type: none"> Providing education regarding heart failure, medication, anticoagulation, dental and skin care, and lifestyle Providing pre- and post-procedural education
Contraception, family planning and pregnancy	<ul style="list-style-type: none"> Providing contraceptive counselling Coordinating preconception counselling Participating in the multidisciplinary pregnancy heart team Supporting patients
Self-care and self-advocacy	<ul style="list-style-type: none"> Assessing patient autonomy Reinforcing self-management Encouraging involvement of family and caregivers
Life expectancy, advance directives and end-of-life care	<ul style="list-style-type: none"> Supporting and coordinating discussions about life expectancy and end-of-life care Ensuring that patient wishes are documented and accessible to care team

From Sillman et al (2017)

nursing teams are responsible for providing a telephone and email helpline service for patients. The nurse provides clinical triage to prioritise calls, assess symptoms and provide appropriate advice. This can facilitate coordination of emergency admissions to local hospitals, while also providing opportunities for patients with ACHD to access advice about lifestyle, work and travel.

The presence of specialist nurses is also required at consultant-led ACHD clinics. Here, specialist nurses provide patients with education about their congenital heart disease, empowering them with the language required to describe their condition, as well as 'red flag' symptoms to highlight when presenting to non-specialist services. Psychological distress related to their heart condition is common in patients with ACHD (Sillman et al, 2017). ACHD nurses proactively identify psychological distress at these interactions and provide appropriate interventions or referral to psychology services. For patients who require multidisciplinary team discussion to determine management, including the need for further intervention, the ACHD nurse provides information about the proposed intervention to the patient and links with the team, advocating for the patient as well as being a clinical expert. Following the multidisciplinary team discussion, the nurse has a role in coordinating outcomes and updating and counselling the patient. In addition, ACHD nurses support the review and management of hospitalised patients, contributing to the care plan and communicating and providing support to the patient and their relatives. Therefore, the ACHD nurse is crucial to the facilitation of advanced care planning and palliative care.

Despite the burden of living with a lifelong cardiac condition, the need for lifelong follow up and, for some, repeated interventions, many people with ACHD are able to attend educational institutions and secure employment. Nurses support patients by providing career counselling, discussing the likelihood of being able to maintain a physical job across their life with complex congenital heart disease, and supporting employers and higher education institutions to plan work or study patterns that are achievable (Girouard and Kovacs, 2020).

In addition to the general components of the role, nurses working within the ACHD specialism can develop sub-specialty expertise. This provides opportunities for ongoing education and development within the role. Sub-specialty areas in ACHD reflect the needs of patients with this condition throughout their lifespan. A key point in the patient pathway is the time of transition from paediatric to adult services. The goal of transition is to:

- Improve the young person's knowledge of their condition
- Inform them how to manage their condition and advocate for themselves
- Help them understand the healthcare system and how to navigate it
- Ensure transfer to specialist adult healthcare services for appropriate follow up (John et al, 2022).

This period is associated with loss to follow up, which can have a significant impact on cardiovascular outcomes (John et al, 2022). While there are different models of transition, the goals are consistent, and nurses play a key role in its success. Mackie et al (2018) described the benefits to self-management, understanding of cardiac disease and follow up with specialist ACHD services through delivery of nurse-led transition. The COVID-19 pandemic led to the rapid adoption of new ways of delivering care, including virtual clinics and remote monitoring. This has provided an opportunity for alternative ways to deliver transition clinics, as well as group sessions and larger transition information events (Horler and Meira, 2021).

Additional sub-specialty roles have developed with the pillars of advanced practice at their core: advanced clinical practice, leadership, facilitation of education and learning and evidence research and development (Royal College of Nursing, 2021). There are common complications that present in adulthood for patients with congenital heart disease and these have become a focus for autonomous nursing roles. Sub-specialty areas that have developed across the UK include heart failure, pulmonary hypertension, cardiac intervention, aortopathy, surgical pathway, arrhythmia and devices, preconception counselling and cardiac obstetrics, and Fontan (single ventricle) clinics. Many of these roles involve advanced clinical assessment, prescribing and advanced decision making. Without a robust evidence base for many treatments in ACHD, nurses working in advanced roles must be able to demonstrate competence and have the support of the specialist ACHD multidisciplinary team when developing and implementing these roles. Patients should confidently expect

that the nurse caring for them has an advanced level of competence to inform practice and to underpin their evolving specialist ACHD role. As patients with ACHD experience a range of cardiovascular complications and interventions, as well as non-cardiac complications, there are vast opportunities for nurses to develop their expertise and develop new aspects of the service within the ACHD team. **Appendix 1** provides examples of ACHD nurses at different stages of their career.

As clinical experts, ACHD nurse specialists have an important role in the education of non-ACHD specialists to support the safe management of these patients (Griffiths et al, 2022). In addition, ACHD nurse specialists can participate and lead on the development of ACHD services to meet the needs of both patients and staff. Advocating for ACHD care, raising awareness and cross-specialty collaboration is important to providing lifelong care.

The British Adult Congenital Cardiac Nurses Association and the future

The British Adult Congenital Cardiac Nurses Association (BACCNA) was founded in 2007 with the following aims:

- To provide a forum whereby nurses with an interest in adult congenital heart disease can communicate and network to promote high-quality care for patients
- To promote the professional development of ACHD nursing, including the definition of roles and competencies, standard setting and the acquisition of appropriate knowledge and skills for competent specialist practice.
- To represent the interests of ACHD nurses at a national and international level
- To promote the sharing of knowledge across the country and the standardisation of practice
- To promote the contribution of nursing to research in ACHD
- To encourage close working relationships with associated organisations, both nationally and internationally (BACCNA, 2019).

In 2015, guidance on roles, career pathways and competence development for ACHD nurses was launched (Royal College of Nursing, 2015). This document provides a framework for nurses working in wards and outpatient settings from ACHD nurse specialists, consultants and educators. However, the landscape of ACHD has changed since 2015 and there have been national developments in nursing practice. For example, the Scottish government's Chief Nursing Office Directorate has launched a review of clinical nurse specialist and nurse practitioner roles in Scotland, providing a definition of these roles, along with an education pathway and competency framework for clinical nurse specialists (Scottish Government, 2021).

To understand the current context of ACHD nursing in the UK, the BACCNA will undertake their first scoping exercise in 2022. This will provide information about the current number of nurses, roles and responsibilities, education and career pathways, as well as assessing the impact of the competency framework. It will detail access to continuing professional development, either by attending ACHD conferences or through postgraduate education. It is important to identify access to advanced practice developmental pathways. Understanding the gaps in ACHD specialist nurse provision across level one, two and three centres will help the BACCNA to develop actions to address these, in conjunction with relevant professional bodies. There is also a need to focus on how to best support the development of future ACHD nurse specialists, as well as working closely with other cardiology nurse specialists who play a role in the management of patients with ACHD when they experience other cardiovascular complications.

Conclusions

The exponential growth in the number of adults with congenital heart disease necessitates provision of specialist ACHD services that meet the needs of these patients and improve outcomes. The medical workforce is struggling to train and recruit at the pace required; the only way to provide specialist care safely, efficiently and effectively for patients with ACHD is to examine the multidisciplinary team and identify who the right professional is for the patient at that point in their pathway. This should not be driven by a lack of medical staff,

Key points

- Congenital heart disease is an abnormality in the structure of the heart that is present from birth. The number of adults with congenital heart disease is increasing, which results in increased use of healthcare services.
- Cardiac and non-cardiac complications of adult congenital heart disease are common and require an understanding of the underlying anatomy and physiology, as well as knowledge of the special considerations and adaptations required to treat these complications.
- Nurses play a crucial role in specialist care for adult with congenital heart disease, supporting patients to live well and using advanced practice to follow up, assess and manage common presentations as part of the multidisciplinary team.

Reflective questions

- Do you know the common cardiovascular presentations of adult congenital heart disease?
- Do you know your local adult congenital heart disease care team and how to contact them?
- How can you support patients with adult congenital heart disease to access the services that they need, including specialist care, cardiac rehabilitation and psychological support?

but instead by the knowledge that ACHD nurse specialists are skilled professionals who play a key role in coordinating care, supporting patients, developing and implementing care plans, developing services, and providing education and leadership. To ensure that ACHD nurse specialists are supported in their development to provide safe care, there is a need for nationally consistent, sustainable and progressive roles, education and career pathways, with investment from service leads and commissioners. Being an ACHD nurse specialist is a challenging, rewarding, dynamic role incorporating truly lifelong care, exposure to a range of cardiovascular diseases, advanced practice and multidisciplinary team working.

Updates regarding ACHD education events can be found at <https://baccna.org.uk/events/> For free access to e-learning for health (assessment and management of acute presentations) in ACHD, visit: <https://www.e-lfh.org.uk/programmes/congenital-heart-disease/>

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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Appendix 1. Examples of adult congenital heart disease care nurses

Adult congenital heart disease advanced clinical nurse specialist—the beginning: David Rodgers and Antonia Docherty, NHS Golden Jubilee, Scotland

David and Antonia were appointed as ACHD advanced clinical nurse specialists in 2021. Both worked as band 5 registered nurses in cardiology, David in the coronary care unit and Antonia in the national services unit, which provides inpatient care for patients with ACHD and patients undergoing advanced heart failure assessment and cardiac transplantation.

David's journey

‘Caring for patients with ACHD in the coronary care unit sparked my interest in the specialty and I knew from that point that I wanted to pursue a career in ACHD. I undertook a Master’s-level module in congenital heart disease, which helped with my professional and personal development.

I was fortunate to successfully achieve my highly desired role of advanced clinical nurse specialist within the Scottish adult congenital cardiac service in June 2021. Since commencing this post, my level of responsibility has increased greatly from my role as a staff nurse. The role includes patient triage via telephone and email, reviewing patients at outpatient clinics and working within a small, specialised team. As a result, effective communication within the team is vital to ensure the delivery of safe, patient-centred care. This role has provided me with the opportunity to develop my skills and knowledge, undertaking Master’s-level modules in advanced clinical assessment and non-medical prescribing to meet the requirements of the advanced clinical nurse specialist role. The opportunity to build long-term, therapeutic relationships with patients and their families is what attracted me to the specialty. This has allowed trust to be formed and allowed me to support patients, as they feel safe in my care.’

Antonia's journey

‘As a staff nurse in the national services unit, I had some experience and knowledge working with patients with ACHD and managing them during their inpatient stay. Learning about different congenital heart disease conditions and working closely with the ACHD specialist team is what attracted me to becoming an ACHD nurse specialist. As I transitioned to this role, the realisation quickly set in that I had a vast amount of learning to do. As an ACHD advanced clinical nurse specialist I assess patients with unusual cardiac anomalies,

often resulting in heart failure treatment in a patient cohort where guidelines are variable. Becoming an ACHD advanced clinical nurse specialist has given me invaluable experience in learning to make autonomous decisions and interpreting results in a patient group in which disease progression is inevitable. Transitioning from registered nurse to advanced clinical nurse specialist has allowed me to undertake specialist competencies and postgraduate qualifications, which has been vital in my personal and professional development. My role as an ACHD advanced clinical nurse specialist is exciting; no two patients are the same and each day brings new learning opportunities and challenges. Learning from senior ACHD advanced clinical nurse specialists has allowed me to become a competent member of the transition team for our patients transitioning over from the paediatrics service. This has given me a sense of purpose in my role. The BACCNA and Royal College of Nursing competency framework plays a pivotal role in providing guidance on ACHD nurse roles, career pathways and competence development. Bridging from staff nurse to advanced clinical nurse specialist has allowed me to be part of the entire patient journey, which is extremely rewarding.'

Adult congenital heart disease advanced clinical nurse specialist: Maggie Simpson, NHS Golden Jubilee, Scotland

'I have worked as an ACHD advanced clinical nurse specialists for 8 years. Before this, I worked in the coronary care unit and the national services unit.

The care and management of patients with ACHD is ever-changing and requires a high level of clinical acumen and continuing professional development across the ACHD and non-ACHD evidence base. Exposure to all aspects of cardiology means that this role is dynamic, and working within a vast multidisciplinary team creates opportunities both to learn and improve patient care and outcomes. The role allows for a unique relationship with patients and their families. It is extremely rewarding to provide and facilitate access to specialist care and support local care for this patient group. Being a resource for patients and empowering them to play a significant role in their own care and outcomes is very satisfying.

I am fortunate to work within a multidisciplinary team who support the development of the nursing team. I currently provide a nurse-led heart failure clinic to patients with complex ACHD. This is underpinned by qualifications in clinical assessment, non-medical prescribing and a heart failure module. This service supports patients to manage their condition and understand heart failure and its disease trajectory. It also supports advanced care planning and facilitates an individualised approach to the initiation and up-titration of guideline-directed medical therapy, referral to the multidisciplinary team for consideration of implantable cardiac devices and advanced heart failure assessment. In addition, I provide a nurse-led preconception counselling service to women with all-cause cardiovascular disease. The development of this aspect of my role has only been possible through the mentorship of the multidisciplinary team and feedback from women about how the service can work for them. Providing women with information to empower them to make decisions about pursuing pregnancy, particularly for those at high risk of adverse events, and facilitating their care within the multidisciplinary team is rewarding and has an impact on their long-term outcomes. It is a privilege to support women and their families through this journey, even when positive outcomes cannot be achieved.

In an ACHD specialism, you can continue to learn and develop your clinical skills for the rest of your career.'

Adult congenital heart disease nurse consultant: Toni Hardiman, Norfolk and Norwich University NHS Trust, England

'Nurse consultants aim to provide better outcomes for patients by improving service quality. Nurse consultants are autonomous practitioners with the competence, skills and authority to practice independently, both professionally and organisationally (Royal College of Nursing, 2015).

In 1997, I started a job as the first specialist nurse in cardiology at the Norfolk and Norwich Hospital, where I first encountered the 'grown-up congenital heart specialty', which was later renamed the ACHD service. I was an experienced coronary care nurse and was quickly involved in the ACHD clinics. It was a rapid, steep learning curve, as I knew

very little about the specialty, but instantly loved the challenge. Being able to support a patient's journey from the age of 16 years to the end of life is a real privilege.

The journey to achieving this role involved completing a Master's qualification in health sciences, as well as additional courses such as independent prescribing and an integrated approach to congenital heart disease module, also at Master's level. I have now been working in the field of ACHD as a specialist nurse for over 20 years, involved in service development, teaching and research. Learning additional skills, such as clinical examination, running a nurse-led rapid access chest pain assessment clinic and developing nurse-led all-ACHD clinics has led to the recognition of my work at an advanced level, consistent with the role of a nurse consultant.

The nurse consultant role involves four main areas of responsibility:

- Expert practice: there is a high degree of autonomy and complex decision making necessary in the care of patients with ACHD. Independent nurse ACHD clinic reviews involve enhanced skills to interpret echo and magnetic resonance imaging results, perform clinical assessments and symptom reviews, and give lifestyle advice. Medication reviews, prescribing and requesting investigations are also part of the role
- Professional leadership and consultancy: involvement in developing advanced practice standards and sharing good practice. Participating in cardiac networks and BACCNA events. Providing advice to professionals involved in all aspects of the patient pathway.
- Education and training: teaching locally and nationally on ACHD conditions and service developments. Supporting students undertaking Master's programmes and encouraging staff development
- Practice and service development, research, and evaluation: developing services to improve the care of patients with ACHD, liaising with multidisciplinary teams and getting involved in clinical research.'