



LJMU Research Online

Lotto, RR, Seaton, S and Griffiths, L

Caring For Patients With Congenital Heart Disease – A Nationwide Survey Of Nurses' Educational Needs

<http://researchonline.ljmu.ac.uk/id/eprint/15989/>

Article

Citation (please note it is advisable to refer to the publisher's version if you intend to cite from this work)

Lotto, RR, Seaton, S and Griffiths, L (2022) Caring For Patients With Congenital Heart Disease – A Nationwide Survey Of Nurses' Educational Needs. British Journal of Cardiac Nursing, 17 (1). ISSN 1749-6403

LJMU has developed **LJMU Research Online** for users to access the research output of the University more effectively. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LJMU Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

The version presented here may differ from the published version or from the version of the record. Please see the repository URL above for details on accessing the published version and note that access may require a subscription.

For more information please contact researchonline@ljmu.ac.uk

<http://researchonline.ljmu.ac.uk/>

CARING FOR PATIENTS WITH CONGENITAL HEART DISEASE – A NATIONWIDE SURVEY OF NURSES' EDUCATIONAL NEEDS

1 INTRODUCTION

With a growing population of patients with Adult Congenital Heart Disease (ACHD), it is essential that nurses have sufficient knowledge and understanding of this heterogenous group of conditions, to provide safe and effective care. This article presents the findings from a national survey examining perceived educational needs.

2 BACKGROUND

Congenital Heart Disease (CHD) is defined as a structural or functional heart defect present at birth (Binocar Working Group, 2013). Advances in paediatric surgical and interventional techniques over the past 60 years, alongside developments in perioperative care and the management of extremely sick babies and children in the critical care environment, has resulted in increasing numbers surviving with complex disease (Neidenbach et al., 2019). There is now an expectation that over 90% of children will survive into adult life (Brida and Gatzoulis, 2020). This has translated into there being at least twice as many adults living with CHD as there are children (Khan and Gurvitz, 2018). In the early years of CHD services many children were discharged from care as practice at the time determined that initial surgery had 'fixed' the problem. It has become increasingly clear that, for most, lifelong care is required, (Saha et al., 2019) with specialist care associated with significantly better outcomes (Diller et al., 2021). However, there is a generation of adults who may not be under appropriate follow up. These patients may be identified when they present with sequelae in adult life, quite

often via emergency routes. In addition, there is a proportion of patients who receive a first diagnosis in adult life; unaware of their heart defect.

CHD services in England have undergone extensive reviews since the 1980s (Kennedy, 2001). The most recent review by NHS England in 2017 highlighted the need for a comprehensive set of standards that are universally implemented (NHS England, 2015). These aim to ensure equitability of access for patients of any age, with care provided as close to home as possible and at the same high standards wherever they are treated.

In order to achieve this, it is imperative that staff have access to education and professional development to ensure high levels of knowledge and understanding of CHD. Section B of the NHS England Standards (NHS (England, 2015) includes minimum staffing level recommendation as well as requirements that each centre must have in place to deliver services and that those staff need to be trained and competent to deliver that care. However, CHD services are delivered by a wide range of providers across an all-age service, and providing meaningful education for that varied workforce is challenging. The British Adult Congenital Cardiac Association (BACCNA) has taken a lead in developing and strengthening education within this area. BACCNA was founded in 2007, with the main aim of provide a forum where nurses with an interest in adult CHD could share practice and network. As part of their focus on education this survey was designed and undertaken, in order to provide a benchmark on which to build.

Aims

The aim of this study is to explore the educational needs of staff who may encounter and support treatment of patients living with CHD. This would provide a better understanding of

their needs and suggest approaches to improve education and knowledge; ultimately resulting in better patient care.

3 METHODS

Ethical approval was obtained, reference 21/NAH/007. To explore the educational needs of staff, a survey was developed and designed by the educational subgroup of BACCNA in May 2020. Questionnaire design is currently one of the most commonly used methods of data collection (Salvador et al., 2020), with ease of national recruitment, speed, and convenience all contributing considerations (Evans and Mathur, 2018). The questionnaire was piloted locally to test face and content validity (Streiner et al., 2015). The Microsoft Forms platform was used in order to facilitate data collection (Evans and Mathur, 2018). All CHD Networks in the UK were invited to share the survey with their staff. Over a period of five weeks between 4/06/2020 and 06/07/2020, the survey was also shared widely on social media by the BCCA (The British Congenital Cardiac Association) and CCNA (Congenital Cardiac Nurse Association). Related operational delivery networks, such as the Neonatal Networks, were invited to share it with their nursing and allied health professional (AHP) colleagues, along with forums such as the RCN Learning Disability nurse forum.

The survey responses were analysed using summary statistics only. We present results as summary tables and bar charts representing the percentage of responses for each survey question. We subsequently focus on two sub groups: Band 5 staff working in any setting; and staff who worked in non-CHD settings, as initial findings highlight raised anxiety levels associated with caring for CHD patients.

4 RESULTS

A total of 513 individual survey responses were received from nurses and AHPs from 04/06/2020 to 06/07/2020. Most respondents were paediatric or neonatal nurses (Table 1, 51.3%) followed by adult nurses (41.7%). Participants responded from every CHD network in the UK. The highest number of responses was from the North West region, which represents the region where the lead for this project works.

Table 1: Summary statistics about the survey respondents

Table 1: Summary statistics about the survey respondents

Characteristics, n (%)	Band 5 staff (n=162)		Staff in non-CHD settings (n=278)		All respondents* (n=513)	
	n	(%)	n	(%)	n	%
Seniority of staff						
Band 5	162	100.0	88	31.7	162	31.6
Band 6	-	-	97	34.9	172	33.5
Band 7	-	-	68	24.5	133	25.9
Band 8	-	-	25	9.0	46	9.0
Type of service						
CHD service	74	45.7	-	-	235	45.8
Non-CHD service	88	54.3	278	100.0	278	54.2
Profession						
Paediatric/Neonatal nurse	98	60.5	188	67.6	263	51.3

Adult nurse	61	37.7	73	26.3	214	41.7
Allied Healthcare Professional	3	1.9	17	6.1	36	7.0
CHD network						
Isle of Ireland	-	-	-	-	4	0.8
Scotland	12	7.4	18	6.5	35	6.8
East Midlands	4	2.5	5	1.8	13	2.5
Evelina London	19	11.7	31	11.2	53	10.3
GOSH and Barts	14	8.6	5	1.8	41	8.0
North East and North Cumbria	19	11.7	13	4.7	36	7.0
North West, North Wales and Isle of Man	46	28.4	96	34.5	174	33.9
Royal Brompton	1	0.6	6	2.2	11	2.1
South West and South Wales	6	3.7	11	4.0	25	4.9
Thames Valley and Wessex	22	13.6	56	20.1	65	12.7
West Midlands	5	3.1	3	1.1	15	2.9
Yorkshire and Humber	14	8.6	34	12.2	41	8.0

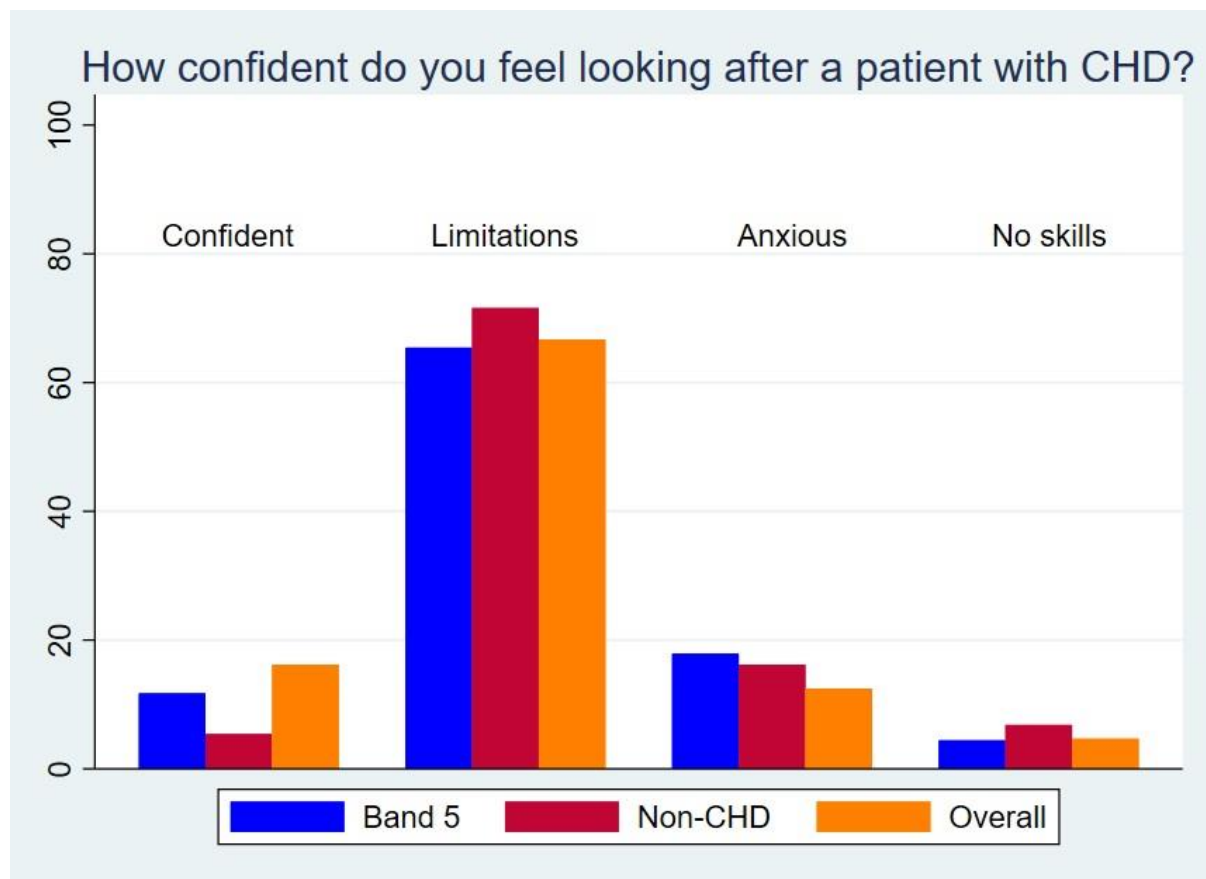
*Note band 5 staff plus non-CHD staff does not equal all staff

Findings from all staff

Overall, 16.2% of staff felt confident when looking after patients with CHD, 67.7% were aware of their limitations, 12.5% were anxious and 4.7% felt that they had no skills at all (Figure 1).

When we focus on the band 5 staff, there was a higher percentage of staff who stated they were anxious (17.9% versus 12.5%) than the overall population. Similarly, staff in non-CHD centres reported higher levels of anxiety than overall (16.2% versus 12.5%).

Figure 1: Overall levels of confidence when looking after a patient with CHD (n=513) and provided for Band 5 (n=162) and staff in non-CHD settings (n=278).

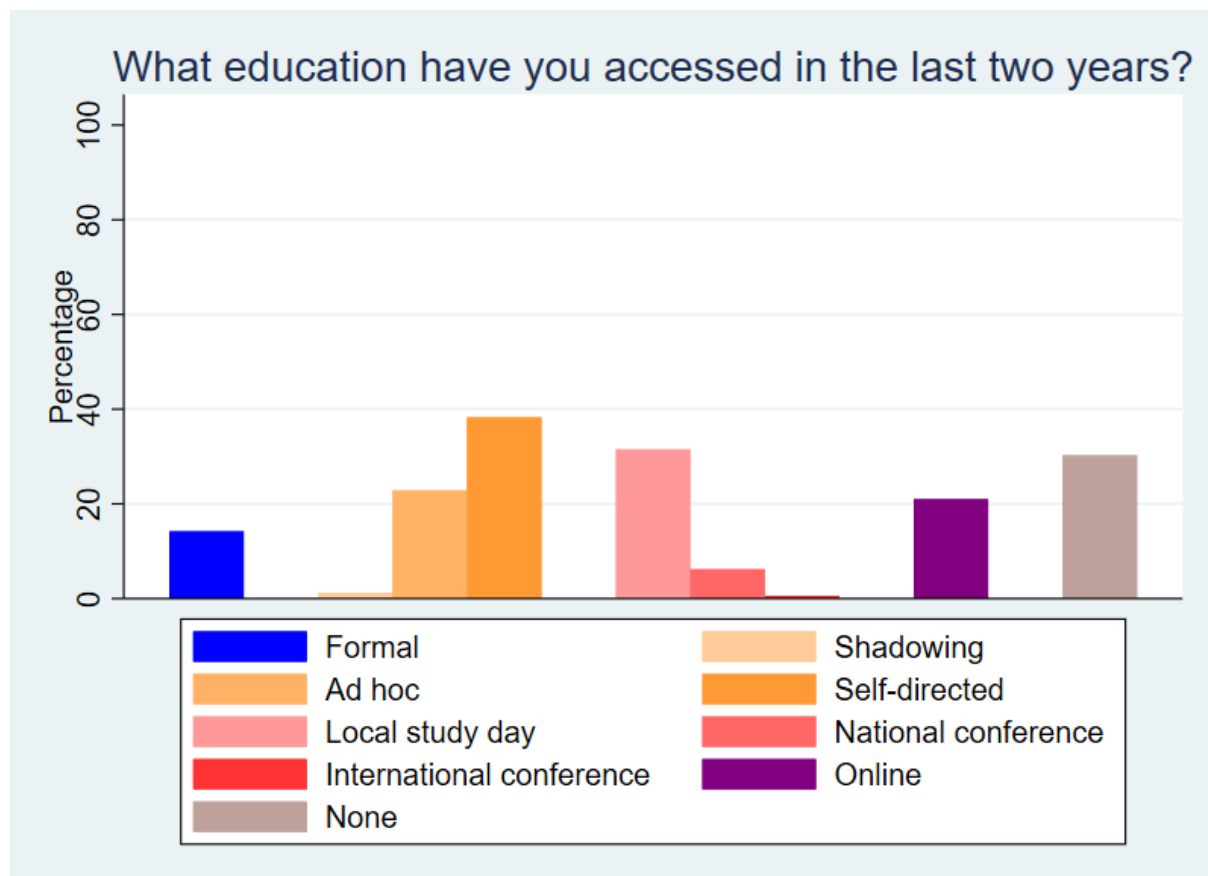


4.1 BAND 5 STAFF NEEDS

Band 5 responders were fairly evenly distributed between CHD and non-CHD settings (45.7 versus 54.3%, Table 1).

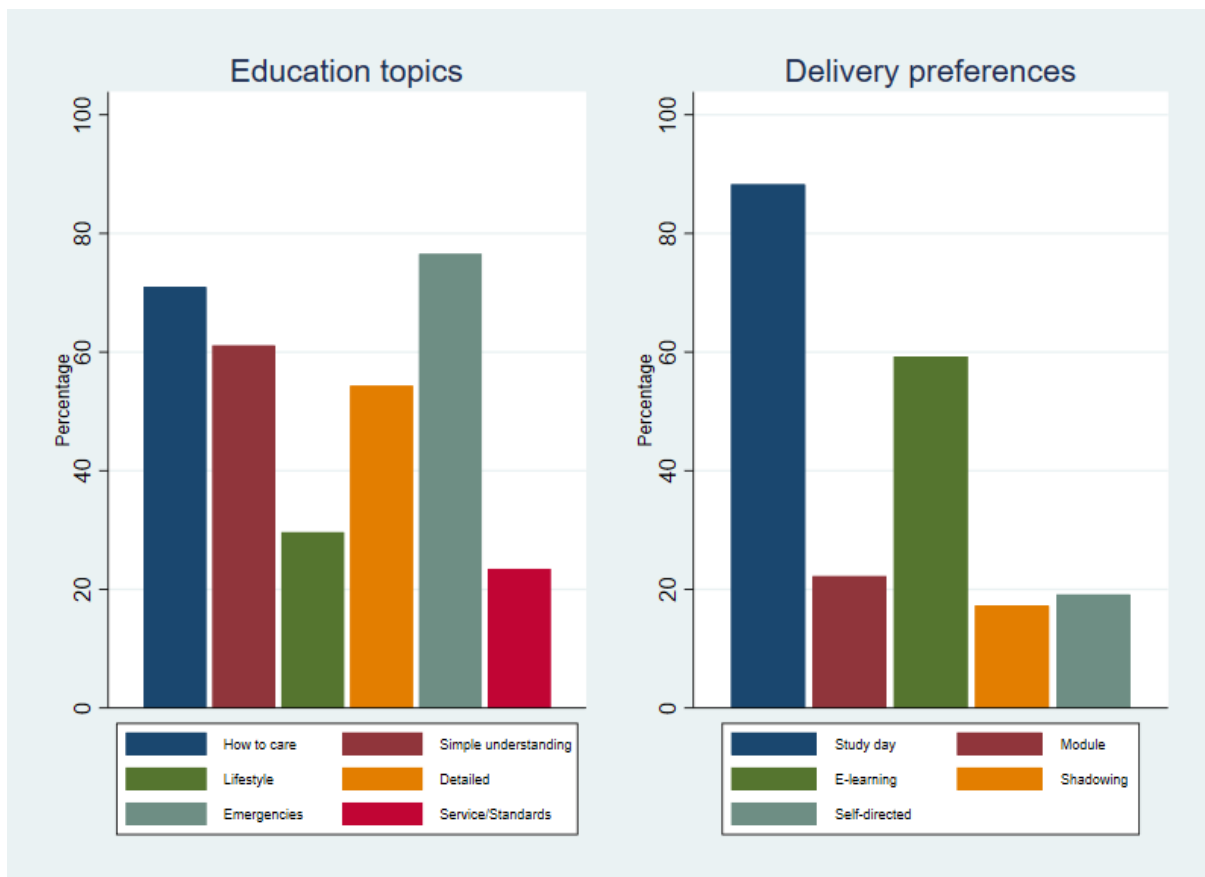
Over the past two years, 30.3% of the 162 band 5 staff reported not having accessed any CHD relevant educational courses. (Figure 2, n=49). Of the staff who had received no training, 28.6% (n=14) were based in CHD settings and the rest were based in non-CHD settings. The most commonly accessed form of education for the band 5 staff was self-directed learning (38.3%), followed by local study days (31.5%).

Figure 2: Previous training in last two years for band 5 staff



The topics band 5 staff identified as being the most useful for their practice included: how to deal with emergencies (76.5%, Figure 3 left hand side); how to care for a patient with CHD (71%); and a simple understanding of CHD (61.1%). The educational non-exclusive options included: self directed study; e-learning; study day; post graduate modules or shadowing, where time would be spent with a more senior colleague. Most band 5 responders preferred the option for a study day (88.3%), followed by e-learning (59%). Shadowing was the least favourable option (around 18%) (Figure 3).

Figure 3: Future training needs for band 5 staff

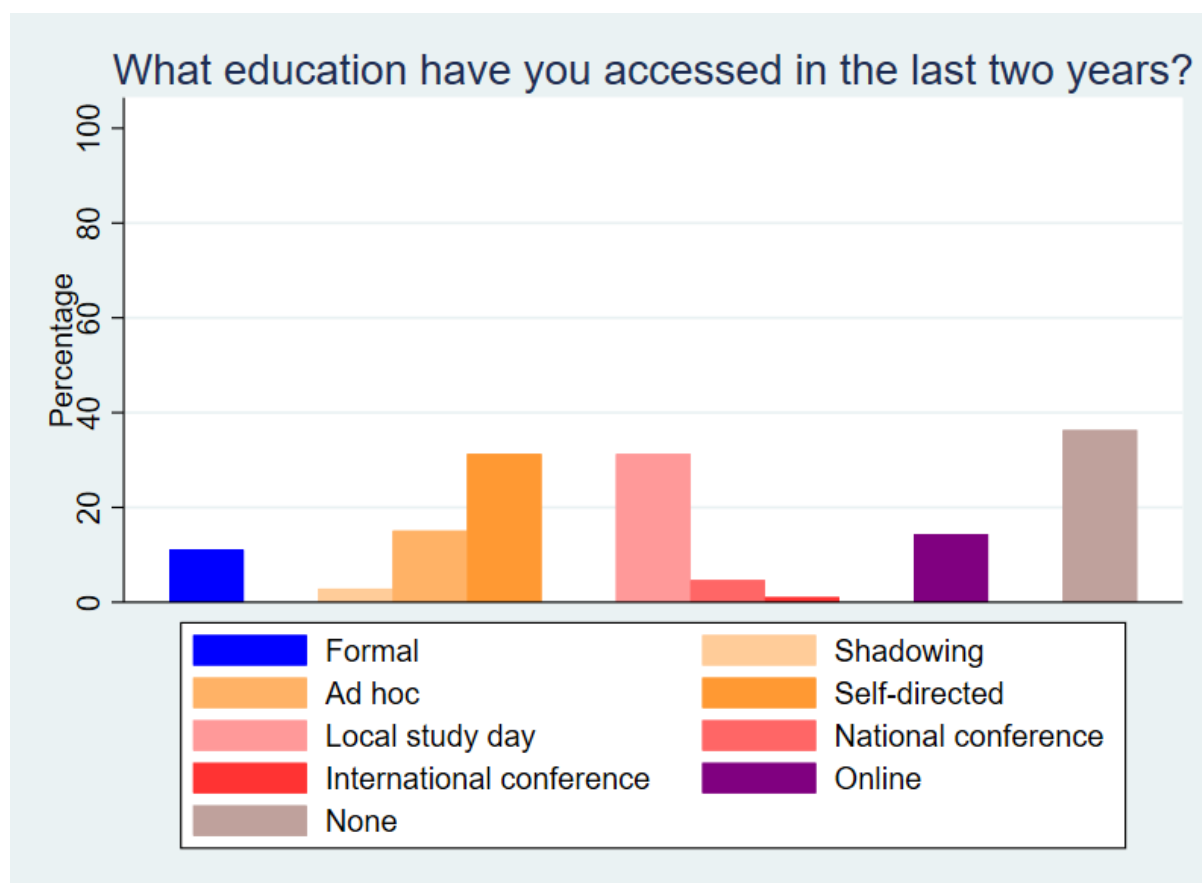


4.2 NON-CHD CENTRE STAFF NEEDS

There were 278 respondents who worked in non-CHD locations (Table 1). Of these, most were paediatric nurses (67.6%, Table 1).

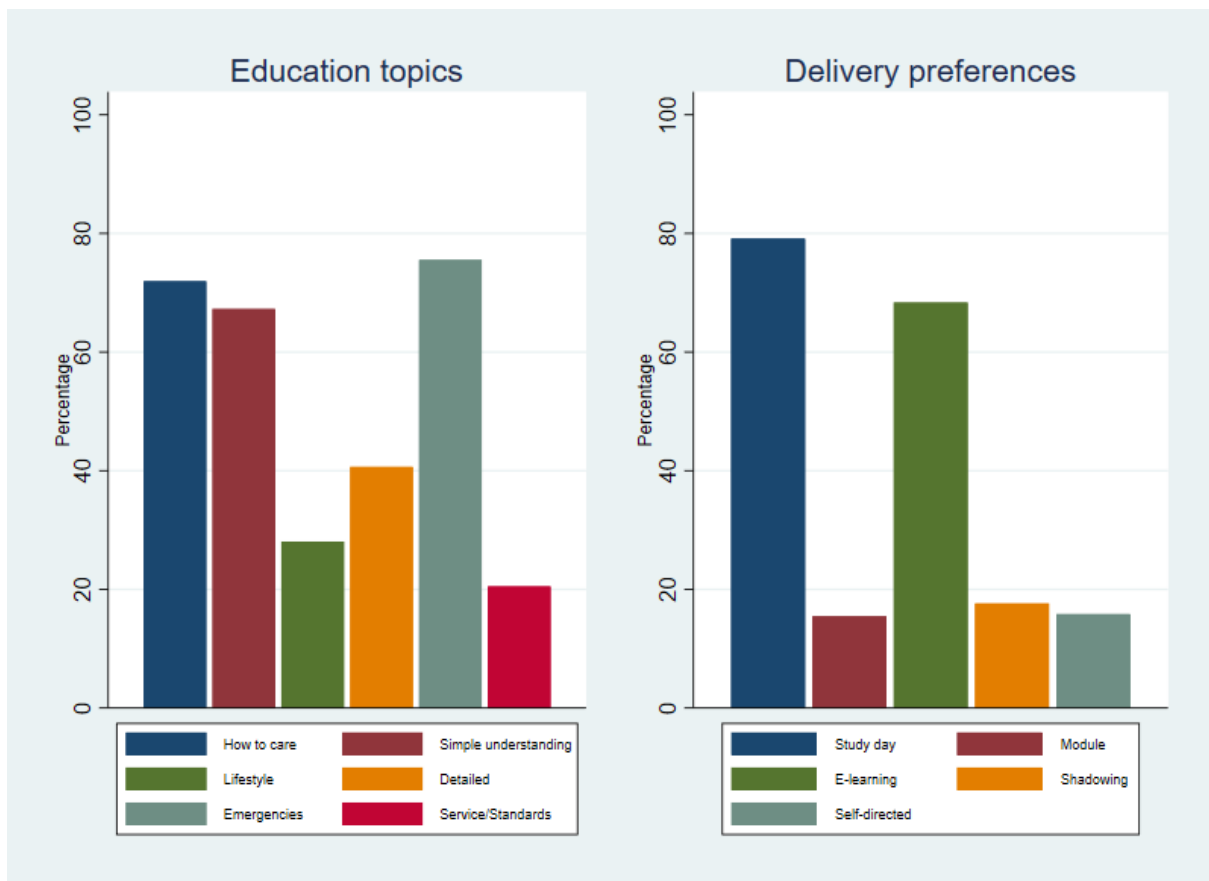
Within non-CHD settings, a high percentage of staff said they had undertaken no CHD training in the previous two years (36.3%, Figure 4). The most commonly accessed educational input was through local study days (31.3%) and self-directed learning (31.3%).

Figure 4: Previous training in the last two years for non-CHD centre staff



Responses from staff based in non-CHD centers reflected those of the band 5 staff, with information about handling CHD emergencies; how to care for patients with CHD; and a simple understanding of CHD, highlighted as the most needed topics (Figure 5).

Figure 5: Future training needs for non-CHD centre staff



Local study days (79.1%, Figure 5) or via e-learning (68.4%) were highlighted as the most accessible forms of delivery, reflecting the needs of the band 5 nurses.

5 DISCUSSION

Nurse education and continued professional development is key to providing CHD patients with consistently high standards of safe, quality care as well as enabling career progression (Biglino et al., 2017; England, 2015; Yeh and King, 2015). In the UK, national standards are in place to ensure optimal care of these patients (England, 2015). This includes explicit requirements around the competence of nurses caring for CHD patients. Evidence from the United States demonstrates a clear correlation between post graduate specialised qualifications and therefore a better understanding of conditions, and outcomes of congenital cardiac patients (Gill, 2018), with similar findings anticipated within the UK. Nonetheless, the provision of appropriate education for nurses to develop and update the skill sets and knowledge required to care for patients CHD is a challenge due to staffing capacity and the personal levels of commitment for lifelong learning (Campbell, 2015).

This survey provides an initial insight into perceived educational needs of those caring for this group of patients. Whilst all grades and levels of nurses and allied health care professionals were invited to participate, higher anxiety levels in more junior staff (namely those working at band 5 level), and staff working in non-CHD specialist hospitals were identified. In addition, these groups were the least likely to have access to, or chosen to access, education or training. Irrespective of their grade, the topics highlighted as important were similar, with managing CHD patients in emergency scenarios prioritised.

Unreflective of the wider nursing and allied health workforce, our sample consisted of more responses from band 6 and above, than staff working at band 5s. This is perhaps unsurprising

as the questionnaire was targeted at those working within a specialist field, who may have had additional qualifications leading to a higher grade role. In addition, although there were marginally more responses from non-CHD centres, the response rate was likely to reflect a higher rate of responses from CHD centres than non-CHD centres. As a result, our findings are likely to have significantly underestimated the true levels of anxiety within the wider workforce.

The data for this survey were collated in the middle of a worldwide pandemic. The impact of this wider context on the findings is unclear. Whilst data regarding aspects such as access to education pre pandemic will not be affected, the immense psychological impact of COVID19 on healthcare professionals (Galehdar et al., 2020), may have influenced broader perceptions of competence. Evidence highlights the heightened anxiety levels experienced by patients with CHD/ACHD, often driven by the uncertainty and subsequent mixed messaging (Marino et al., 2021; Wray et al., 2021). This is likely to have increased workload and subsequent levels of anxiety within the healthcare workforce generally.

Nonetheless, these findings provide an initial insight from which upskilling of the workforce can be planned. Currently, a substantial proportion of staff are not accessing further education, with those able to undertake further study, predominantly engaging in self-directed reading, online webinars or single local study days. Whilst different training and educational approaches are important in provision of optimal learning, formal study days, supported by an easy access digital model were the heavily favoured methods.

Mobile and e-learning technology is increasingly favoured by 'younger' generations of nurses, with students actively encouraged to engage with educational apps, with benefits including

improvements in knowledge and confidence, and reduced levels of anxiety (O'Connor and Andrews, 2018). Formal study remains difficult to access, with barriers including lack of time, (Dyck and Kim, 2018) access to resources and cost concerns (Bindon, 2017) often cited as reasons for not engaging. However, with training and education directly linked not only to patient outcomes, but to nurses' career satisfaction, the need to invest in continuing professional development opportunities is paramount. (Price and Reichert, 2017)

6 CONCLUSION

There is a clear need for ongoing staff development and education within the field of CHD. Our survey highlights specific needs within those nurses working at a band 5, and those working within a non-CHD centre. Many have not accessed any educational updates in recent years, and report a high level of anxiety when caring for this group of patients. The preferred mechanisms of delivery are formal educational sessions, along with some form of digital solution, such as an app. Emergency management and a simple understanding of key care requirements were highlighted as priority areas.

7 REFERENCES

Biglino, G., Capelli, C., Koniordou, D., Robertshaw, D., Leaver, L.K., Schievano, S., Taylor, A.M., Wray, J., 2017. Use of 3D models of congenital heart disease as an education tool for cardiac nurses. *Congenital heart disease* 12, 113-118.

Bindon, S.L., 2017. Professional development strategies to enhance nurses' knowledge and maintain safe practice. *AORN journal* 106, 99-110.

Brida, M., Gatzoulis, M.A., 2020. Adult congenital heart disease: past, present, future. *International Journal of Cardiology Congenital Heart Disease*, (1) 100052. <https://doi.org/10.1016/j.ijcchd.2020.100052>

Campbell, J.M., 2015. Education and simulation training of pediatric intensive care unit nurses to care for open heart surgery patients. *Critical care nurse* 35, 76-81.

Diller, G.-P., Orwat, S., Lammers, A.E., Radke, R.M., De-Torres-Alba, F., Schmidt, R., Marschall, U., Bauer, U.M., Enders, D., Bronstein, L., Kaleschke, G., Baumgartner, H., 2021. Lack of specialist care is associated with increased morbidity and mortality in adult congenital heart disease: a population-based study. *European Heart Journal*.42(41) 4241–4248

Dyck, M.J., Kim, M.J., 2018. Continuing education preferences, facilitators, and barriers for nursing home nurses. *The Journal of Continuing Education in Nursing* 49, 26-33.

Evans, J.R., Mathur, A., 2018. The value of online surveys: A look back and a look ahead. *Internet Research*. 28(4)

Galehdar, N., Kamran, A., Toulabi, T., Heydari, H., 2020. Exploring nurses' experiences of psychological distress during care of patients with COVID-19: A qualitative study. *BMC psychiatry* 20, 1-9.

Gill, F.J., 2018. Pediatric Critical Care Nursing Education and Certification Really Matters. *Pediatric Critical Care Medicine | Society of Critical Care Medicine* 19, 779-780.

Kennedy, I., 2001. Bristol Royal Infirmary Inquiry; Learning from Bristol: the Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995. The Stationary Office, London.

Khan, A., Gurvitz, M., 2018. Epidemiology of ACHD: what has changed and what is changing? *Progress in cardiovascular diseases* 61, 275-281.

Marino, L., Wagland, R., Culliford, D., Bharucha, T., Sodergren, S., Darlington, A.-S.E., 2021. "No Official Help Is Available"—Experience of Parents and Children With Congenital Heart Disease During COVID-19. *World Journal for Pediatric and Congenital Heart Surgery* 12, 500-507.

Neidenbach, R., Achenbach, S., Andonian, C., Beckmann, J., Biber, S., Dittrich, S., Ewert, P., Freilinger, S., Huntgeburth, M., Nagdyman, N., 2019. Medical care of adults with congenital heart diseases: Present and future. *Herz* 44, 553-572.

NHS England., 2015. New Congenital Heart Disease Standards. <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

O'Connor, S., Andrews, T., 2018. Smartphones and mobile applications (apps) in clinical nursing education: a student perspective. *Nurse education today* 69, 172-178.

Price, S., Reichert, C., 2017. The importance of continuing professional development to career satisfaction and patient care: meeting the needs of novice to mid-to late-career nurses throughout their career span. *Administrative Sciences* 7, 17.

Saha, P., Potiny, P., Rigdon, J., Morello, M., Tcheandjieu, C., Romfh, A., Fernandes, S.M., McElhinney, D.B., Bernstein, D., Lui, G.K., 2019. Substantial cardiovascular morbidity in adults with lower-complexity congenital heart disease. *Circulation* 139, 1889-1899.

Salvador, P, Alves, K., Rodrigues, C, Oliveira, L., 2020. Online data collection strategies used in qualitative research of the health field: a scoping review. *Revista gaucha de enfermagem* 41.

Streiner, D.L., Norman, G.R., Cairney, J., 2015. *Health measurement scales: a practical guide to their development and use*. Oxford University Press, USA.

Wray, J., Pagel, C., Chester, A.H., Kennedy, F., Crowe, S., 2021. What was the impact of the first wave of COVID-19 on the delivery of care to children and adults with congenital heart disease? A qualitative study using online forums. *BMJ open* 11, e049006.

Yeh, D.D., King, M.E., 2015. Congenital heart disease in the adult: what should the adult cardiologist know? *Current cardiology reports* 17, 25.