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Determinants of outpatient clinic attendance amongst adults with congenital heart disease and outcome

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ABSTRACT

Background: Adult congenital heart disease (ACHD) guidelines advise life-long, regular, follow up in predefined intervals for ACHD patients. However, limited data exist to support this position. We examine, herewith, compliance to scheduled outpatient clinic appointments and its impact on outcome.
Methods and results: We examined 4461 ACHD patients (median age at entry 26.4 years, 51% female) and their follow up records at our tertiary centre between 1991 and 2008. Clinic attendance was quantified from electronic hospital records. For survival analysis we employed the last clinic attendance before 2008 as starting of follow-up. Overall 23% of scheduled clinic appointments were not attended. The main predictors of clinic non-attendance (CNA) were younger age, non-Caucasian ethnicity, lower socioeconomic status, number of previous CNAs and the lack of planned additional investigation/s (e.g. echocardiography) scheduled on the same day. During a cumulative follow-up time of 48,828 patient-years, 366 (8.2%) patients died. Both, the number of CNAs (HR = 1.08, 95% CI 1.05–1.12 per CNA, $P < 0.001$) and the ratio of CNA to follow up period (HR = 1.23, 95% CI 1.04–1.44 per CNA/year, $P = 0.013$) emerged as predictors of mortality independent of adjustment for patients' age, disease complexity, functional class and socioeconomic status.
Conclusions: Patient adherence to scheduled ACHD outpatient-clinics is associated with better survival. Identifying patients at an increased risk of CNA in a single tertiary centre is feasible. Our data provides previously lacking evidence supporting the practice of periodic assessment of ACHD patients at tertiary clinics. Non-attenders should be specifically targeted and receive counselling to modulate their increased risk of death.

1. Introduction

Adult congenital heart disease (ACHD) patients represent an increasing population with high resource utilization [1,2]. Despite ongoing research and improvements in care, morbidity and mortality remain considerable [3].

It is now recognized that notwithstanding reparative intervention/s during childhood, patients with congenital heart disease have not been "cured" [4]. There are late complications, which impact on quality of life and survival [5–8]. Overt symptoms may be late or catastrophic i.e. sudden cardiac death, whereas the identification of patients at risk remains challenging. It is, thus, recommended that ACHD patients are assessed regularly at specialized centres. Guidelines go further, providing disease specific intervals for outpatient clinic visits, ranging from 6 months in complex cyanotic patients to 5 years in patients with simple defects and no residual lesions [9–11].

Such a proactive approach of regular follow-up visits to ACHD clinics, although intuitively safer, is resource-intensive and, surprisingly, lacks robust evidence to support it.

We set to examine predictors of outpatient clinic attendance and its impact on outcome in our large, single centre, tertiary ACHD practice.

2. Patients and methods

Data on all adult patients with congenital heart disease under follow-up at our tertiary centre before 2008 were retrospectively obtained and studied. Patients' clinical data, demographics, data on all clinic appointments, both attended and non-attended, as well as the number and type of tests were retrieved from electronic patients' records. Patients had their appointments booked at the time of their

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previous visit. Additionally, all patients, irrespective of whether additional tests were booked for the day or not, were sent an invitation letter several weeks prior to the scheduled clinic appointment. Very occasionally, when such a letter may be returned, the responsible secretary contacts the patient's general practitioner to verify the current address of the patient and informs him or her of the scheduled appointment for the mutual patient. We do not, at present, operate a policy of calling patients or sending emails or texts prior to outpatient clinic visits. Clinic non-attendance (CNA) was defined as non-attendance to the original clinic appointment or re-scheduling that delayed the patient's outpatient clinic visit. Sensitivity analysis was performed accounting for CNAs causing a delay in care provision of 3 months or more.

There is a national support system for low-income patients with partial or complete reimbursement of travel costs. There are local social services working with general practitioners and clinical nurse specialists within our catchment area providing support for our patients, ensuring that access to and delivery of care is uniform.

Patients were grouped by ACHD complexity based on the Bethesda Conference classification [12]. Socioeconomic status was assessed indirectly using the English Index of Multiple Deprivation 2007 (IMD 2007) — a measure of deprivation at the small area level, as previously described [13]. Briefly, it combines 38 indicators distributed across seven domains, including income, health, employment and education, disability, skills and training, barriers to housing and services, crime and living environment. For each domain a score is calculated, which is then ranked (the most deprived neighbourhood is given a rank of 1). In addition, a total score and rank of deprivation is calculated. The results are provided at lower layer super output area (LSOA) level which was matched to the residential postcode. Travel distance and time were obtained using a custom written script in R for Windows, which retrieved the data from web-based route planner. Mortality data were retrieved from the national database and are complete. This study was approved by the local ethical review board.

3. Statistical analysis

Statistical analysis was performed using R-package version 2.15.0 [14]. Continuous variables are presented as mean ± standard deviation or median and interquartile range (IQR), presented in square brackets, depending on data distribution. Categorical variables are presented as number (percentage). Data distribution was assessed for normality using the Shapiro–Wilk test. Comparison between groups was performed using Wilcoxon rank sum test or Chi-squared test, depending on type of data. Parameters assessing socioeconomic status are used in the statistical analyses as standard score calculated from IMD scores. The relation between likelihood of clinic attendance and various parameters was assessed for each appointment in each patient using a generalized linear mixed model employing the *lme4* package. The relation between clinical and demographic parameters as well as outpatient clinic attendance and mortality was assessed using Cox proportional-hazards regression analysis. For this purpose we have used patients' status on the last attended clinic appointment before 2008 as the start date (Fig. 1). Follow up time was calculated from this appointment until the date of death or the censoring date for survivors (01 Sep 2013). In the multivariate models we have included a stratification for the era of the first outpatient clinic appointment with periods starting in 1995 with 5-year spans. The number of CNAs and further parameters related to CNAs in the survival analysis relate to appointments before the follow-up start date. A two-sided *P*-value of <0.05 was considered indicative of statistical significance.

4. Results

In total, 4461 patients were included in the analysis. Demographic and clinical characteristics of all patients are presented in Table 1 and in the supplement. Median age at the first recorded appointment was 26.4 years and 51% patients were female. According to the Bethesda classification 1907 (43%) patients had a simple lesion, 1622 (36%) a moderate and 863 (19%) a complex lesion; 69 (2%) patients had a lesion not classified in the Bethesda conference document. The majority of patients were asymptomatic or mildly symptomatic (NYHA functional class I or II in 65% and 28%, respectively). Most patients were of white ethnicity (70.6%). Overall, 36% patients were residents of the Greater London metropolitan area. The median travel distance for all patients to our centre was 26.8 miles [11.6–55.6 miles], corresponding to a median travel time of 51 min [32–88 min].

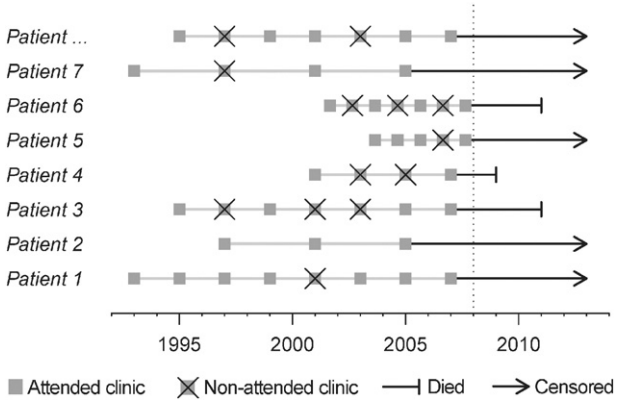

Fig. 1. Title: Schematic representation of the survival analysis. Legend: All patients under follow up between 1991 and 2008 were included. All outpatient clinic appointments before 2008 were classified as "attended" or "non-attended". Clinical status and other parameters were assessed at the last appointment before 2008, which also served as time zero for the follow-up in the survival analysis.

5. Outpatient clinic attendance

There was a significant increase in clinical workload over time, the number of outpatient clinic appointments increased from a median of 827 [791–1048] appointments per year in the early era (1991–1995) to 3184 [3166–3240] per year in the late era (2006–2010), Fig. 2. The overall incidence of CNAs was 23.4% and it increased over the study period from 15.5% to 26.0% (early vs. late era, $P < 0.001$).

The median interval between clinic assessments in years was 1.0 [0.7–1.5] for simple, 1.0 [0.7–1.3] for moderate and 0.8 [0.6–1.1] for great complexity ACHD lesions. The intervals for patients with great complexity ACHD were shorter, compared to patients with mild or moderate complexity lesions ($P < 0.001$ for both comparisons), whereas there was no such difference between simple and moderate lesions ($P = 0.2$). Several parameters emerged as significant predictors of CNA (Fig. 3) including non-white ethnicity (OR 1.22, 95% CI 1.13–1.33, $P < 0.001$), previous CNA (OR 1.14, 95% CI 1.08–1.20, $P < 0.001$), and indices of socioeconomic deprivation. Additional investigation/s booked at the day of clinic appointment had a positive effect on clinic attendance (OR for CNA of 0.49, 95% CI 0.46–0.53, $P < 0.001$). There was also a weak, but nevertheless significant association of younger age and CNA (OR 0.97 per 10 years of age, 95% CI 0.95–1.00, $P = 0.017$). Gender, complexity of ACHD and travel distance/time were not predictive of clinic attendance.

6. Mortality and predictors of outcome

During a cumulative follow up period of 48,828 years (median follow-up 9.6 years), 366 (8.2%) patients died. Overall, 60% of deaths were directly related to cardiovascular causes, 10% due to pneumonia, 6% due to haemorrhage, 4% due to cancer, 4% due to sepsis (without confirmed endocarditis), 7% due to mixed other causes, whereas in 9% of patients the cause of death was unknown. On survival analysis,