

## Short Communication

# Life-long Cardiac Surveillance of Patients with Severe Congenital Heart Disease: are we Adhering to Guidelines?

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Guidelines for adults with congenital heart disease (ACHD) stipulated over 15 years ago, that life-long specialized care is vital for severe CHD and patients should receive yearly follow-up visits [1]. Prior studies investigated the occurrence of care gaps during the transfer from pediatrics to adult-focused healthcare and reported gaps occurring in 7-76% [2]. As these studies focused exclusively on adolescents, the issue of guideline implementation along patients life spectrum remains understudied. We investigated adherence to recommendations on cardiac surveillance over an important course of a patient's life in a setting with universal access to health insurance, where policy mandates a transfer to adult services at 18y.

The Québec CHD database systematically records all diagnoses and healthcare services provided to CHD patients from 1983 to 2010 [3]. For this study, we identified 4,713 patients with severe CHD, living in Québec, aged 12-65y, who had at least two years of follow-up during the observation period (2001-2010). Although we could have excluded all patients over the age of 18 in 2001, we chose not to

do so because at that time patients with CHD were often followed in pediatric centers well into adulthood. Pediatric care providers would thus be subject to being influenced by guidelines affecting patients as they became young adults. We have defined severe CHD as forms of CHD that had the highest probability of being associated with cyanosis at birth as detailed and validated in our first publication to use this definition in 2007 [4] and subsequently used by ourselves [5-15] and others [16]. We computed the average yearly rate of outpatient visits with a specialized pediatric or CHD cardiologist formulated as the total number of visits divided by the total number of follow-up years. Based on this average rate, we categorized patients into three groups. The first group represented patients who were considered to be adherent to the recommendations (i.e. average yearly visit rate  $\geq 1$ ) [1,17]. The second group comprised patients who had visits occurring less than yearly on average but had at least one visit during the observation period. The third group had no cardiac outpatient visits during the observation period, although they had contact with the healthcare system. The latter two groups were

considered as non-adherent, with the third group further categorized as being lost to cardiac follow-up. To assess if adherence varied by age, we categorized patients into three age groups (i.e., 12-24years; 25-40years; 41-65years). The first group reflects the transition period in young people. We hypothesize that the second group experiences a fairly stable health status with lesser symptoms and lower healthcare consumption, whereas the oldest group represents multi-morbidities, reflecting a higher need for care.

About one-fourth of the patients received follow-up in line with recommendations, with a drop to 20.7% in 25-40y cohort. Within the adherent group, the average visit rate was 1.83 (SD: 1.36), 2.78 (SD: 3.06), and 3.55 (SD: 4.20) in the three age groups, respectively. The proportion of patients categorized as non-adherent but still in cardiac follow-up, was 38.6%, 40.9% and 27.4% in the three age groups, respectively. The average visit rate in these groups was 0.43 (SD: 0.23), 0.34 (SD: 0.22), and 0.44 (SD: 0.24), respectively. The proportion of patients lost to cardiac follow-up significantly increased over the age groups from 34.8% in the youngest up till 47.4% in the oldest group [ $\chi^2=50.7694$ ;  $p<0.00001$ (Figure 1)].

This study was the first to investigate guideline adherence on cardiac surveillance across different age groups. Irrespective of age, at least 70% did not receive cardiac follow-up according to the guidelines with notable care gaps increasing with age. Indeed, up to 47% did not have any cardiac follow-up visit during the study period. These findings demonstrate that most adults with CHD are not receiving follow-up in keeping with guidelines advocated and published by ACHD experts in the USA [17], Canada and Europe.

In the absence of guidelines for follow-up prior to 2001, one cannot make assumptions about patterns of follow-up in a new and emerging population. Our study was designed to look at the impact of

guidelines. We thus chose measures of follow-up that could be compared before and after 2001. Although recommendations on cardiac follow-up in patients with severe CHD have been reiterated over the past decade by professional associations, implementation rates remain to be low. Debates regarding scientific rigor of these expert-based guidelines are ongoing, as the evidence base for continuous stratified life-long care is currently scarce and the allocation rules might appear arbitrary. These recommendations serve, however, as the only uniform guidance for clinicians and researchers to allocate the level and frequency of follow-up care in ACHD to date. In this study, we are showing that adherence rates not only appeared problematic during the transition period, but over the entire lifespan of adults with complex CHD. In light of evidence showing that specialized ACHD care reduces mortality [3], the consequences of life-long care gaps need to be investigated. Population-based studies using a longitudinal design are highly needed to assess the impact of care gaps on morbidity, mortality and healthcare use in patients with CHD. If care gaps and non-adherence to cardiac follow-up guidelines are as prevalent, in a healthcare system with universal health insurance, it is unlikely that care gaps are less prevalent where variation in insurance policies might be a barrier for access. International studies, in which different healthcare systems are compared and outcomes of care gaps are assessed, are needed. Expansion of the evidence base is of paramount importance to provide an empirical basis for adaptation, expansion or confirmation of the current practice guidelines on cardiac follow-up, lifting them from eminence- to evidence-based.

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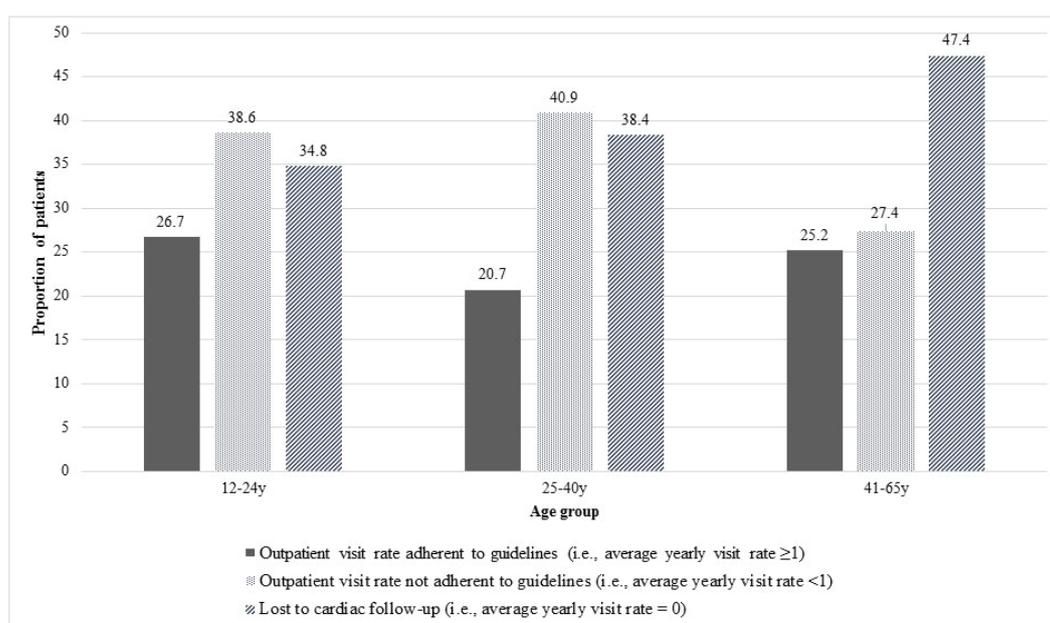


Figure 1: Proportion of patients across groups, stratified by age.

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## Disclosures

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