The systemic right ventricle
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Letter to the editor regarding article “Children and adults with congenital heart disease lost to follow-up: who and when?”

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The author’s reply

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TO THE EDITOR

In their recent paper, Mackie et al. demonstrated that 61% of adult patients with congenital heart disease (CHD) in Quebec fail to receive cardiac follow-up. In the Netherlands we found that only one third ($n=8,000$) of adult patients with CHD fail to receive cardiac follow-up. Therefore, caution with extrapolating these data to other nations is recommended.

On average 200,000 children are born in the Netherlands each year. With a birth prevalence of around 8 per 1,000 live births, and an overall survival rate until adulthood of 85% since the early '70, there are an estimated 25,000 adult (and 25,000 pediatric) survivors of CHD in the country. In 2000, the Interuniversity Cardiology Institute of the Netherlands and the Netherlands Heart Foundation took the initiative to develop a national registry and DNA-bank of adult patients with CHD; CONCOR. In January 2009, over 10,000 patients were registered in CONCOR, including almost all patients followed-up in one of the 8 Dutch university hospitals ($n=7,500$), and 2,500 patients from non-university hospitals. Moreover, trained research nurses have visited all non-university hospitals in the Netherlands, and were able to identify another 7,000 adult patients with CHD who are yet to be included in the registry. In summary, thanks to the success of CONCOR we know that 17,000 patients receive cardiac care in the Netherlands, which leaves approximately 8,000 patients that fail to receive cardiac care. These numbers are significantly lower compared to the 61% described by Mackie et al.  

We postulate that there are two main reasons for this discrepancy. Mackie et al. state that the prevalence of CHD is 4.09 per 1000 adults, whereas our calculation is founded on the birth prevalence of 8 per 1000 live births. Using different methods to calculate the number of patients with CHD, subsequently leads to different numbers of patients who are lost to follow-up. A second explanation for the discrepancy between the number of patients that fail to receive cardiac care could be the geographic differences between Quebec and the
Netherlands. Being 37 times smaller, with twice the number of inhabitants, it is never an issue to receive adequate cardiac care close to home.

Although the number of patients that fail to receive follow-up is lower in the Netherlands compared to Quebec, we still thought it was unacceptably high. To increase awareness of this problem and retrieve patients with CHD that were lost to follow-up we initiated a nationwide media campaign entitled: “Wanted! 8000 Heart Patients”. Six months ago we started our campaign with billboards throughout the country, which generated attention by patients and the media. Until now, our campaign has lead to articles in newspapers and magazines, and to exposure on national radio and television. Within the first 6 months, we received applications from over 800 subjects with CHD. The success of our campaign is a great stimulus to continue our efforts to increase awareness in the general population, and retrieve those patients who are lost to follow-up.


THE AUTHORS’ REPLY

We appreciate the letter from Winter et al about our study entitled, “Children and Adults With Congenital Heart Disease Lost to Follow-Up: Who and When”.

The collaborative effort in the Netherlands among healthcare providers who care for patients with adult congenital heart disease (ACHD) should be admired for raising public awareness and for bringing previously lost patients back into ACHD care. We agree with these authors that variation in rates of loss to follow-up inevitably exists. These differences likely relate to a variety of factors, including not only differences in geography, as Winter and colleagues point out, but also differences in healthcare funding, availability of ACHD expertise, and resources available to identify and seek patients lost to follow-up. As we pointed out in the Discussion section of our article, patients with ACHD face challenges with employability and insurance, and in jurisdictions without universal healthcare coverage, unlike Canada and the Netherlands, the proportion of patients with ACHD lost to follow-up may be even higher.

There are several important differences in the methodology that we used and the methodology described by Winter et al. We followed a cohort consisting of all people born with congenital heart disease in Quebec in 1983 who were diagnosed before 6 years of age and were still alive in 2005. Therefore, we were certain as to the denominator (ie, the number of patients needing follow-up). Winter and colleagues have estimated the ACHD population in the Netherlands at 25,000, but this is not based on an actual measurement. With an adult population in February 2009 of approximately 12.9 million, we would anticipate that the ACHD population in the Netherlands would actually number 52,700 adults if its prevalence among adults is similar to the 4.09/1000 measured in Quebec.

Although the number of patients with ACHD still receiving cardiology care is important, so too is the training and expertise of the treating cardiologist(s). The Netherlands group acknowledges that 9500 patients were receiving cardiology care in nonuniversity hospitals. Many patients with ACHD in Canada also are not followed up in specialized ACHD centers. Media campaigns and patient driven
organizations\(^5\) may help us close this gap. Unfortunately, the number of ACHD-trained cardiologists is insufficient to meet the needs of this rapidly growing population. To that end, we may follow the example set by our colleagues in the Netherlands by initiating a media campaign entitled, "Wanted: ACHD Doctors!"


