Congenital Heart Disease in Canada: What Are We Missing?

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“My heart condition affects where I choose to live, where I choose to work, what I choose to study, where I feel comfortable vacationing, if I’ll have children. It affects everything.”


Presently 180,000 people are living with congenital heart disease (CHD) in Canada: of these 100,000 are age > 18 years.\textsuperscript{1} Prevalence of CHD far exceeds that of more publicized diseases such as Parkinson’s (75,000), multiple sclerosis (50,000), cerebral palsy (3,600) and cystic fibrosis(3,600). And the adult CHD population continues to grow each year. The current expectation for newborns with CHD is that more than 95% will survive into adulthood.\textsuperscript{2,3} Many adults with CHD are at life-long risk of complications and premature death.\textsuperscript{3,4,5} Lapse of follow-up care is a known risk factor for morbidity.\textsuperscript{6}

The Canadian Adult Congenital Heart Network (CACHnet) was established in 1991 to provide expert care of adults with CHD in 15 specialty clinics across the country.\textsuperscript{7} The CACHnet system is an internationally recognized model of care. In addition, the Canada Health Act ensures access quality health care without financial or other barriers. But in spite of this highly organized nation-wide system of free expert care, 77% of adults with CHD in Canada do not attend these specialty clinics for follow-up care.\textsuperscript{8} Adults “lost to follow-up” may not know they need expert care or that expert care is available and they may do poorly without care.

Recent efforts to improve transition of care from pediatric to adult care may help to retain future CHD patients.\textsuperscript{9,10,11} But little progress has been made in finding adults already lost from the system. When these adults are found they will flood a system that might be unable to cope with the substantial increase in numbers.

For adults lost to follow-up, the 2009 Canadian Cardiovascular Society recommendation that adults with CHD receive life-long care is not being met.\textsuperscript{6} There is a large gap in Canada between needs and the availability of resources and personnel.\textsuperscript{1,8,9,11,12} A vibrant patient group is needed to advocate for adequate resources, education and research.
To fill this need, the Canadian Congenital Heart Alliance (CCHA) was established in 2004 as a national non-profit organization committed to improving the quality of life, health outcomes, education and research for patients of all ages with CHD.

The CCHA conducted an Internet survey in 2012 to gain insight into the current needs of adults with CHD. The survey was advertised to the CCHA membership and through social media. Survey results are available on our CCHA website (www.cchaforlife.org/resource-centre/ccha-patient-survey-2012-results.html) and Facebook page (see Appendix). The purpose of this communication is to bring attention to issues identified in our survey.

**Selected Survey Observations and Comments:**

The survey attracted 124 participants, a miniscule proportion of adults with CHD. The majority of these (91%) are followed in a CACHnet clinic and most are “very satisfied” or “satisfied” with their care. Those not satisfied with care report lack of confidence in their cardiologist, being rushed during appointments, long travel distance, long wait for treatment, and feeling like a “guinea pig” instead of a person. Insufficient coordination of tests and consultations at the time of a clinic visit was another recurring theme. Respondents also expressed that their general practitioners and community cardiologists lacked awareness and training in CHD. It is important to note, however, that our survey results are biased towards adults already in the system. Reasons given for not seeing a specialist included: “There isn’t one where I live”, “I didn’t know I was supposed to see one”, and “I am waiting for an appointment.”

“I would love to have someone to talk to more about my fears and challenges I impose on myself. I would love to feel like my doctor doesn’t see me as just a number and would spend more than 30 seconds with me once a year.”

Of greatest concern to respondents are: health concerns related to their heart condition, emotional challenges, general health, employment, and mobility. What respondents felt would be helpful is someone to talk to, more help managing their health care, and greater resources to cope with challenges and disabilities.

“I've never had my cardiologist ask/offer/refer me to a psychologist even when I clearly could have used one. I would love to have access.”
Challenges cited included low self esteem, sexual and reproductive issues, trying to change from a sedentary lifestyle to a more active one, anxiety and depression about future healthcare issues, difficulty getting insurance, and difficulty keeping up with peers.

“I worry about taking long trips to countries with poor health care and I try not to get into serious relationships because of fear of not being able to have children or dying early.”

When asked how their heart defect has impacted their education or career, comments included difficulty at school, difficulty moving “up the ladder” or switching careers, and fatigue.

“I would never tell my employer for fear of my condition being used against me. Such as if I was to try and gain job promotion.”

Most respondents felt their heart condition affects life choices, impacting their education, occupation, travel, and child-bearing.

The age of one half of the respondents is 30 to 50 years. The majority (56%) live in Ontario with small numbers in 7 other provinces. There was no participation from Manitoba, Prince Edward Island, Northwest Territories, Yukon or Nunavut. Among the latter 5, only Manitoba has a CACHnet clinic.

Annual income was more or less evenly distributed across the range of $15,000 to $100,000.

Marital status: married (46%), single (25%), divorced (4%), common law (3%) and other.

Only 39% reported working full time, including 9% who are self-employed.

Access to care is available within 100 km of home for 3/4 of respondents. Most drive to clinic appointments; public transit is used by few adults.

Only half have access to affordable life insurance (through employer or parents) and about 1/3rd are able to access affordable travel insurance.

Respondents were asked how much they felt they would benefit from each of the following: consultations with a dietician, social worker, psychologist, financial planner and meeting other congenital heart patients. All were highly valued, especially consultation with a psychologist, a counsellor and meeting other heart patients. When asked if their cardiologist referred them to any of the above, they said it was uncommon.
Discussion:

The survey proves, if nothing else, that reaching the ‘silent majority’ of adult CHD patients is difficult. We are unable to clarify why this is so, nor why only 23% of adults are followed in the CACHnet system. Our survey results must be interpreted as the thoughts of ‘the converted’.

Perhaps a national publicity campaign to raise awareness of CHD might encourage return to expert care of some adults lost to follow-up, though when such a strategy was attempted in Canada some years ago, it had very modest success (Gary Webb MD, personal communication). Multiple strategies, especially making use of social media and other on-line methods of communication may be more productive.

Respondents to the CCHA survey report general satisfaction with their health care and wellbeing. They also identify issues where improvements could be made: notably psychosocial support, employment opportunities, and professional advice regarding nutrition and exercise.

These issues require coordination of resources within the existing medical system. For example diet, nutrition and exercise are very important but can be dealt with through general medical and non-medical resources. Adult CHD programs lack expertise in these areas and to develop these would detract from the primary purpose of providing expert cardiac follow-up care. Identical issues apply to psychosocial support and career counselling. Facilitating referrals requires breaking down the silos inherent in Canadian health care.13

Lack of proximity to specialty care is a reality related to the large geographic size of Canada. Internet communication may solve some of the isolation issues in future but for the present, support for travel expenses is needed for patients from remote areas.

Inferences:

The adult CHD patients who completed our survey are generally satisfied with their care. But very few patients responded. The majority of adult CHD patients in Canada are not receiving recommended care in spite of the highly organized national CACHnet system of clinical expertise provided free of charge. To understand and engage the enigmatic ‘silent majority’ of adult CHD patients we need better patient education starting at an early age, improved transition of care, streamlined referrals to non-cardiac clinics from CACHnet clinics and more research in
adult CHD. CCHA is committed to foster quality of life and health outcomes for CHD survivors by raising awareness, providing peer support, advocacy, and advancing research.

References


**Appendix:**

We received 129 responses to the survey distributed in February 2012 from 318 members of CCHA. Of these, 124 are CHD patients. A follow-up survey in April 2012 had 100 responses. Consent to participate was implied by virtue of responding to the questionnaire.

Quantitative and thematic qualitative analyses of the surveys, supported by verbatim quotations from the respondents are shown in italics within quotation marks and illustrate the verisimilitude of the data.

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